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SUPPLEMENTAL SECURITY INCOME PROGRAM

JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES

OF THE

COMMITTEE ON WAYS AND MEANS

AND THE

SELECT COMMITTEE ON AGING

HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

MARCH 2, 1989

Serial 101-6

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SUPPLEMENTAL SECURITY INCOME PROGRAM

THURSDAY, MARCH 2, 1989

House of Representatives, Committee on Ways and Means, Subcommittee on Human Resources; and Select Committee on Aging,
Washington, D.C.

The committees met in joint session, pursuant to notice, at 1:09 p.m., in room 1100, Longworth House Office Building, Hon. Edward R. Roybal (chairman of the Select Committee on Aging), and Hon. Thomas J. Downey (acting chairman of the Subcommittee on Human Resources) presiding.

[The press release announcing the hearing and background material for the hearing follow:]

FOR IMMEDIATE RELEASE
TUESDAY, FEBRUARY 14, 1989

PR #2
SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES
1102 LONGWORTH HOUSE OFFICE BUILDING
WASHINGTON, D.C. 20515
TELEPHONE: (202) 225-1721

THE HONORABLE THOMAS J. DOWNEY (D., N.Y.), ACTING CHAIRMAN, SUBCOMMITTEE ON HUMAN RESOURCES, COMMITTEE ON WAYS AND MEANS, AND THE HONORABLE EDWARD R. ROYBAL (D., CALIF.), CHAIRMAN, SELECT COMMITTEE ON AGING, U.S. HOUSE OF REPRESENTATIVES, ANNOUNCE A JOINT HEARING ON THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

The Honorable Thomas J. Downey (D., N.Y.), Acting Chairman of the Subcommittee on Human Resources, Committee on Ways and Means and the Honorable Edward R. Roybal (D., Calif.), Chairman of the Select Committee on Aging, U.S. House of Representatives, today announced a joint hearing on the Supplemental Security Income (SSI) program. The hearing will be held on Thursday, March 2, 1989, beginning at 1:00 p.m., in room 1100 Longworth House Office Building.

In announcing the hearing Chairman Downey said, "I am pleased to join with Chairman Roybal for this SSI hearing. It has been several years since we have carefully reviewed the SSI program. I am especially interested in learning more about how SSI recipients are coping and what it's like to live on the SSI benefit level." Chairman Roybal commented on the hearing as follows: "I have become increasingly concerned about the inadequate benefit levels, great gaps in service, and outdated eligibility requirements which characterize SSI. I commend Acting Chairman Downey for his leadership in calling for this important hearing."

BACKGROUND:

The SSI program is the nation's basic cash welfare program for the aged, blind and disabled. It is a Federally-administered program authorized by title XVI of the Social Security Act. Established in 1972 and implemented in 1974, SSI provides monthly cash payments in accordance with uniform, nationwide eligibility requirements to needy aged, blind and disabled persons. The current Federal-benefit level is $354 monthly for a single person and $532 monthly for a couple. A lower benefit level has been established for persons in shared households.

In 1988, there were more than 4.4 million SSI recipients. Federal costs for the program totaled more than $12.3 billion in fiscal year 1988. In addition, many States supplement the Federal SSI benefit using State funds. In 1988, these supplementary payments totaled $3.2 billion.

(MORE)

At this hearing, oral testimony will be limited to invited witnesses only. Witnesses are expected to discuss the adequacy of the current benefit level, the special problems of disabled children and ways to improve outreach and prevent potential recipients from falling through the cracks.

In order to assure the most productive use of the limited amount of time available to question witnesses, all witnesses scheduled to appear are required to submit 75 copies of their prepared statements to the Ways and Means Committee office, 1102 Longworth House Office Building, at least 24 hours in advance of their scheduled appearance. Failure to comply with this requirement may result in the witness being denied the opportunity to testify in person.

DETAILS FOR SUBMISSION OF WRITTEN COMMENTS:

Any interested person or organization may file written comments for inclusion in the printed record of the hearing. Persons submitting written comments for the printed record should submit at least six (6) copies of their comments by the close of business, Friday, March 17, 1989, to Robert J. Leonard, Chief Counsel, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. If those filing written comments for the record of the printed hearing wish to have their comments distributed to the press and interested public, they may deliver 75 additional copies for this purpose to the hearing room on the date of the hearing.

SEE FORMATTING REQUIREMENTS BELOW:

Each statement presented for printing to the Committee by a witness, any written statement or exhibit submitted for the printed record or any written comments in response to a request for written comments must conform to the guidelines listed below. Any statement or exhibit not in compliance with these guidelines will **not** be printed, but will be maintained in the Committee files for review and use by the Committee.

1. All statements and any accompanying exhibits for printing must be typed in single space on legal-size paper and may not exceed a total of 10 pages.
2. Copies of whole documents submitted as exhibit material will not be accepted for printing. Instead, exhibit material should be referenced and quoted or paraphrased. All exhibit material not meeting these specifications will be maintained in the Committee files for review and use by the Committee.
3. Statements must contain the name and capacity in which the witness will appear or, for written comments, the name and capacity of the person submitting the statement, as well as any clients or persons, or any organization for whom the witness appears or for whom the statement is submitted.
4. A supplemental sheet must accompany each statement listing the name, full address, a telephone number where the witness or the designated representative may be reached and a topical outline or summary of the comments and recommendations in the full statement. This supplemental sheet will not be included in the printed record.

The above restrictions and limitations apply only to material being submitted for printing. Statements and exhibits or supplementary material submitted solely for distribution to the Members, the press and public during the course of a public hearing, may be submitted in other forms.

BACKGROUND MATERIALS

FOR A JOINT HEARING BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES OF

THE COMMITTEE ON WAYS AND MEANS

AND THE

HOUSE SELECT COMMITTEE ON AGING

"SUPPLEMENTAL SECURITY INCOME (SSI)"

MARCH 2, 1989

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H.R. 360: "SSI Asset Reform Act of 1989"

H.R. 361: "SSI Benefit Level Reform Act of 1989"

H.R. 866: "SSI Benefit Improvements Amendments of 1989"

H.R. 867: "SSI Technical Amendments of 1989"

H.R. 868: "SSI Disabled and Blind Children Act of 1989"

"THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM"

March 2, 1989

SSI - Program Authorization or Intent

Authorized by Title XVI of the Social Security Act in 1972 (P.L. 92-603), the SSI program began in 1974 to provide a nationally uniform guaranteed minimum income for the aged, blind, and disabled. SSI has national uniform standards to determine program eligibility. The minimum cash grant is wholly federally financed by general revenues and administered by the Social Security Administration (SSA).

Eligibility

Program eligibility includes persons age 65 and over, or blind, or disabled people of any age, whose income and resources are below specific levels and who meet other requirements.

The following definitions are used:

Aged: Persons 65 years and older.

Blind: Persons with 20/200 vision or less, with the use of corrective lenses in the person's better eye, or those with tunnel vision of 20 degrees or less.

Disabled: Persons unable to engage in substantial gainful activity, due to a medically determined physical and/or mental impairment, expected to result in death, or that has lasted or can be expected to last for at least 12 months. Also, a child under 18 who has an impairment of comparable severity with that of an adult may be considered disabled.

Federal Benefit Standard

The amount of the monthly Federal SSI payment is determined by the recipient's countable income, living arrangement, and marital status. The SSI benefit standard is the floor of income assured by the program for people with no countable income.

In 1989, the Federal SSI benefit standard for an individual, living in his own household, with no countable income, is $368 a month, or about $12/day. For a couple, the monthly benefit standard is $553.

Actual benefit payments are computed by subtracting the individual's/couple's countable income from the benefit standard.

The Federal SSI benefit standard is indexed annually to the CPI by the same percentage as Social Security benefits.

Income (Earned and Unearned)

Income is defined as the earnings, Social Security checks, annuities, and other checks and cash one receives. Income can also mean any items one receives instead of cash, such as food or shelter.

Income Disregard — some income is not counted in determining eligibility. Currently, $20 of monthly income from any source, usually Social Security for the aged, is disregarded. In addition, the first $65 a month one earns, plus one-half of the remaining earnings, is not counted in determining eligibility. The value of in-kind assistance provided by federally assisted or state or local government programs (for example, nutrition services, food stamps, housing or social services), are also disregarded.

Individuals and couples applying for or receiving SSI benefits are determined to be eligible if their countable income does not exceed certain income benefit standards.

Maximum Income for Eligibility for Federal SSI Benefits, 1989

	Receiving Only Social Security		Receiving Only Wage Income	
	Monthly	Annually	Monthly	Annually
Individual	$388	$4,656	$821	$9,852
Couple	$573	$6,876	$1,191	$14,292

Assets (Resources)

SSI eligibility is restricted to qualified persons who have countable assets of less than a specific amount. When the program was first established, the assets standard for a person living alone was $1,500; for a couple, it was $2,250. In 1989, the asset limit is $2,000 for an individual and $3,000 for a married couple. The asset test is not presently tied to increases in the Consumer Price Index. Consequently, since SSI began in 1974, the asset eligibility standard has been cut virtually in half in inflation-adjusted terms.

Assets are defined as things one owns such as real estate, personal belongings, savings and checking accounts, cash, stocks and bonds.

Some assets are not counted: the home one lives in, household goods and personal effects with a limit of $2,000 in equity value, $4,500 of the current market value of a car (and if one uses it for medical treatment or employment it is totally excluded); burial plots for individual and immediate family members; a maximum of $1,500 in burial funds for an individual and a like amount for one's spouse.

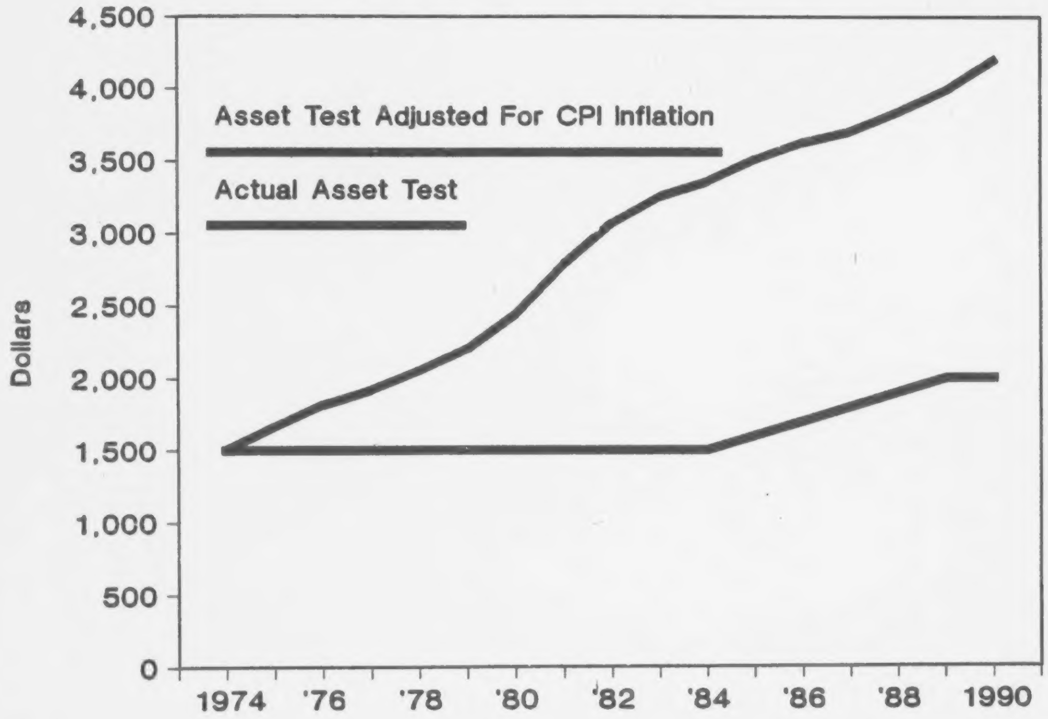
The income of an ineligible spouse who lives with the SSI recipient or applicant is considered in determining the eligibility and amount of benefits paid to the individual.

Dependent Living Arrangements

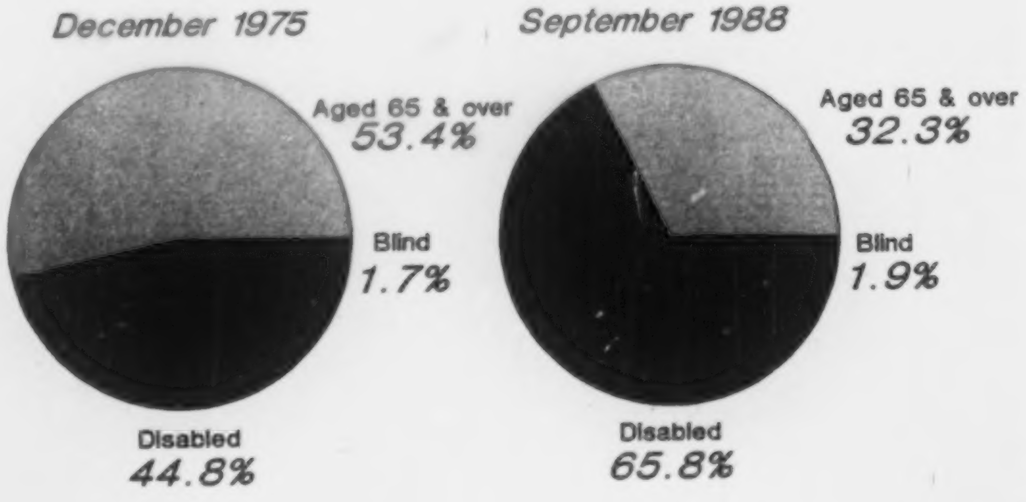
If an applicant or recipient is living in another person's household and receiving support and in-kind maintenance from a person, such as groceries, the value of the assistance is presumed to equal one-third of the regular Federal SSI benefit standard.

When an SSI recipient enters a hospital or other medical institution in which a major portion of the bill is paid by Medicaid, the SSI benefit level is reduced to $30. This amount is intended to take care of personal needs, such as hair cuts, newspapers, toilet articles, etc.

History of SSI Asset Test Levels For Individuals
Actual Levels Compared With Inflation Adjusted Levels

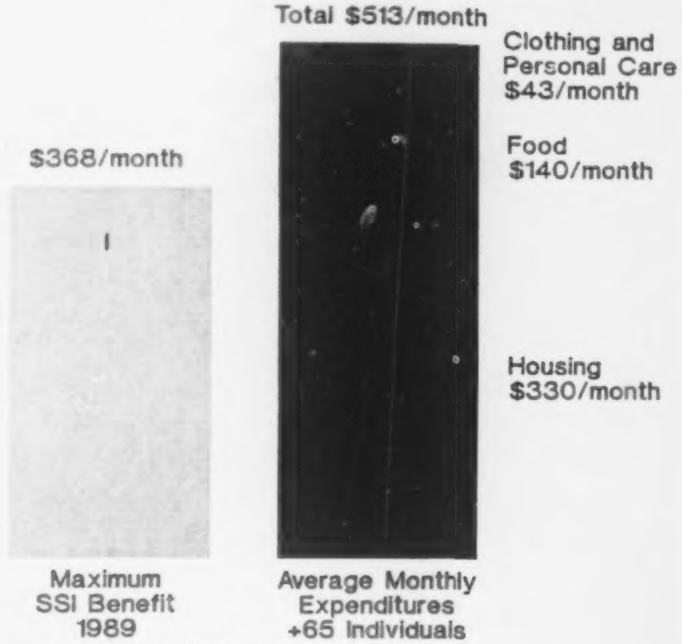


SSI: Percentage Distribution of Persons Receiving
SSI Payments, by Reason for Eligibility:
December 1975 and September 1988



Source: Ways and Means Committee

1989 Federal SSI Benefit Level Compared With Average Monthly Expenditures Of Individuals Age 65 and Over



Source: Bureau of Labor Statistics - Consumer Expenditure Survey - 1986 Figures Adjusted For Inflation

DEMOGRAPHIC AND ECONOMIC CHARACTERISTICS OF SSI RECIPIENTS

As of September, 1988, about 4.434 million individuals receive SSI. Approximately one-third, or 1.434 million recipients, are eligible on the basis of age; over half, 2.917 million, are eligible on the basis of disability and 1.9%, 82,740, are eligible on the basis of blindness.

The number of aged receiving SSI has declined substantially since 1975 from 2.3 million to 1.434 million in 1988.

Of SSI recipients who are eligible based upon age, 40.7% are 80 years and older, compared to 21% of the population 65 years and over who are 80 and older.

In 1988, women comprised three-fourths of those entitled to SSI on the basis of age, and nearly three-fifths (58.4%) of those entitled on the basis of disability.

Blacks comprise 19.7% of SSI recipients eligible based upon age and 28% of SSI recipients who are eligible based upon disability.

Persons of Spanish origin comprise approximately 11% of the SSI population.

Over half (57%) of all SSI recipients are women not living with a spouse. Almost three-fourths (72%) of aged SSI recipients and one-half (50%) of disabled SSI recipient are women not living with a spouse.

Only 1.4% of aged SSI recipients have earned income.

Most SSI recipients (70%) live in metropolitan areas. Sixty-five percent of aged recipients and almost 72 percent of disabled recipients reported metropolitan residence.

Social Security benefits are received by 70% of aged SSI recipients. In 1940 less than one percent of recipients of Old Age Assistance also received Social Security.

Comparison of Combined Benefits to Poverty Thresholds
For Individuals Receiving SSI & Social Security

	Calendar Year			
	1975	1982	1986	1989
Poverty Threshold	$2,572	$4,630	$5,255	$5,950
Fed. SSI Benefits:				
Dollars Per Yr.	$1,822	$3,294	$4,032	$4,416
% of Poverty	70.8	71.1	76.7	74.2
Fed. SSI & Social Security				
Dollars Per Yr.	$2,062	$3,534	$4,272	$4,656
% of Poverty	80.2	76.3	81.3	78.3

PROGRAM PARTICIPATION

Program participation rates have been consistently low throughout the program's history. Recent serveys reveal little or no public understanding of the SSI program.

A July 1986 national survey, commissioned by the Commonwealth Fund Commission on Elderly Living Alone, and conducted by Louis Harris and Associates, revealed that only one-half of all older persons eligible for SSI participated in the program. When asked why they do not participate, over half of the individuals responded that they had never heard of SSI or believed that they were not eligible.

Possible participation barriers include a lack of information or misinformation about eligibility criteria, the inability or unwillingness to deal with the program's bureaucratic procedures, the negative stigma associated with welfare receipt, the fear of the loss of privacy, and the perception of low benefits.

1988 SSI Outreach Demonstration Project

A 1988 study sponsored by the American Association of Retired Persons (AARP) and the Commonwealth Fund Commission on Elderly People Living Alone revealed that an average of 48.5 percent of eligible older people are not enrolled in SSI. Participation rates varied substantially among the 22 states surveyed, ranging from 27% to 63.8%

To address this situation, AARP, with support from the Commonwealth Fund and through the active cosponsorship of the local Area Agency on Aging in three cities, formed a coalition of approximately 40-50 agencies to assist with a five month demonstration SSI outreach project. The project was conducted in 3 demonstration sites, (El Paso, Texas; Pittsburgh, Pennsylvania; and Oklahoma City, Oklahoma) and was designed to serve as a model for similar outreach efforts which might be implemented throughout the country.

A primary goal of the project was to increase the number of SSI applications and awards recorded in each of the demonstration sites. Statistical data were obtained from the Social Security Administration analyzing monthly applications and awards showing that in each site, aged applications and awards rose substantially.

Results of Outreach Demonstration Projects

SSA offices in the three cities reported receiving 97 percent more applications which yielded 58 percent more awards than during the previous three years.

Pittsburgh, Pennsylvania showed the greatest increase over the pre-demonstration period: 157% for applications and 68% for awards. Increases in Oklahoma City, Oklahoma were 43% for applications and 56% for awards; and in El Paso, Texas increases were 50% for applications and 49% for awards. Together, the three sites processed an average of 164 more aged SSI applicants per month since the outreach project began and an average of 65 more aged awards per month. Those individuals awarded SSI benefits in Pittsburgh and El Paso were also automatically eligible for the Medicaid program.

Based upon the success of the project, AARP recently announced that in 1989 they are seeking cosponsors in 10 communities to coordinate other local SSI outreach projects. In three of the selected sites the focus of the project will be to conduct outreach activities to specific minority populations.

STATE SUPPLEMENTATION

For individuals who had been covered under state Old Age Assistance (OAA) programs prior to enactment of the SSI program, federal law requires states to supplement an SSI recipient's benefits to a level equal to the amount they had been given under OAA. **Only approximately 42% of SSI recipients receive a state supplement.**

Presently 26 states and the District of Columbia supplement the Federal standard for individuals living independently. Between 1975 and January 1988, only 3 States — California, Michigan, and Oklahoma — increased supplements to aged individuals living independently faster than inflation. And only 3 other states — Alaska, Colorado, and New Hampshire — kept benefit levels for these individuals even with inflation over that time period.

The state supplement may be issued by the states or the state may elect Federal administration of the state supplement.

If the Federal government administers the state supplement, applications may be filed with SSA. The Federal benefit standard and the supplement are combined in one check issued by the Federal government.

If the state administers its own supplement, application for the supplement is made at a local welfare office and the supplemental check is mailed separately.

The amount of the supplement varies from state to state (from $2/month to $384/month for an individual) and reflect differences in regional living costs. **The median state supplement in January 1989 for aged individuals living independently is $36/month - or about $1 per day.** For aged couples, the median state supplement is $60/month. (See charts on next two pages).

—STATE SSI SUPPLEMENTS FOR AGED INDIVIDUALS WITHOUT COUNTABLE INCOME LIVING INDEPENDENTLY [1]

State	July 1975	July 1980	Jan. 1985	Jan. 1986	Jan. 1987	Jan. 1988	Jan. 1989	Percent increase (constant dollars) 1975–89 [1]
Alaska [2]	$142	$235	$261	$269	$292	$305	$317	0
California	101	164	179	197	220	221	234	4
Colorado	27	55	58	58	58	58	58	0
Connecticut	NA	NA	NA	NA	NA	393	384	....
District of Columbia	0	15	15	15	15	15	15	....
Hawaii	17	15	5	5	5	5	5	−87
Idaho	63	74	78	72	73	73	73	−48
Illinois [3]	NA	NA	NA	NA	NA	NA	NA	....
Maine	10	10	10	10	10	10	10	−55
Massachusetts	111	137	129	129	129	129	129	−48
Michigan	12	24	27	28	29	30	30	11
Minnesota [4]	31	34	35	35	35	35	35	−49
Nebraska	67	75	61	62	51	43	38	−74
Nevada	55	47	36	36	36	36	36	−71
New Hampshire	12	46	27	27	27	27	27	0
New Jersey	24	23	31	31	31	31	31	−42
New York	61	63	61	72	72	72	86	−37
Oklahoma	27	79	60	64	64	64	64	6
Oregon	17	12	2	2	2	2	2	−95
Pennsylvania	20	32	32	32	32	32	32	−29
Rhode Island	31	42	54	56	56	59	61	−13
South Dakota	0	15	15	15	15	15	15	....
Utah	0	10	10	10	9	9	9	....
Vermont	29	41	53	56	57	58	60	−8
Washington [5]	36	43	38	28	28	28	28	−65
Wisconsin	70	100	100	102	102	103	103	−34
Wyoming	0	20	20	20	20	20	20	....
Median [6]	31	43	36	36	36	36	36	−48

---

[1] The percentage decrease in constant dollars was computed by inflating July 1975 to January 1989 by the CPI–U price index. A January 1989 figure of 361.6 was used. The July 1975 CPI–U was 162.3.

[2] 1975 and 1980—less if shelter costs less than $35 monthly.

[3] State decides benefit on a case-by-case basis.

[4] Payment level for Hennepin County. State has 10 geographic payment levels.

[5] State has two geographic payment levels—highest levels are shown in table. Sum paid in King, Pierce, Kitsap, Snohomish, and Thurston Counties.

[6] Among the States with a payment, Connecticut and Illinois are classified as having a payment above the median.

Source: Office of Research and Statistics and Office of Supplemental Security Income, Social Security Administration.

—STATE SSI SUPPLEMENTS FOR AGED COUPLES WITHOUT COUNTABLE INCOME LIVING INDEPENDENTLY

State	July 1975	July 1980	Jan. 1985	Jan. 1986	Jan. 1987	Jan. 1988	Jan. 1989	Percent increase (constant dollars) 1975–89 [1]
Alabama	$9	0	0	0	0	0	0	−100
Alaska [2]	183	$338	$371	$383	$427	$444	$462	13
California	251	389	448	485	529	534	563	0
Colorado	133	229	278	284	116	116	292	−1
Connecticut	NA	NA	NA	NA	NA	602	551	....
District of Columbia	0	30	30	30	30	30	30	....
Hawaii	28	24	9	9	9	9	9	−85
Idaho	49	80	46	40	44	44	43	−61
Illinois [3]	NA	NA	NA	NA	NA	NA	NA	....
Maine	15	15	15	15	15	15	15	−55
Massachusetts	173	214	202	202	202	202	202	−48
Michigan	18	36	40	42	44	45	45	13
Minnesota [4]	38	44	66	66	66	66	66	−22
Nebraska	67	114	89	92	78	66	60	−60
Nevada	106	90	74	74	74	74	74	−69
New Hampshire	0	42	21	21	21	21	21	....
New Jersey	13	12	25	25	25	25	25	−14
New York	76	79	76	93	93	93	102	−40
Oklahoma	54	158	120	128	128	128	128	7
Oregon	17	10	0	0	0	0	0	−100
Pennsylvania	30	49	49	49	49	49	49	−27
Rhode Island	59	79	102	105	106	111	115	−12
South Dakota	0	15	15	15	15	15	15	....
Utah	0	20	20	20	18	18	18	....
Vermont	61	76	96	101	104	106	109	−20
Washington [5]	40	44	37	22	22	22	22	−75
Wisconsin	105	161	161	164	164	166	166	−29
Wyoming	0	40	40	40	40	40	40	....
Median [6]	57	63	66	66	66	66	60	−53

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[1] The percentage decrease in constant dollars were computed by inflating July 1975 to January 1989 by the CPI–U price index. The July 1975 CPI–U was 162.3. A December 1988 figure of 361.6 was used.

[2] 1975 and 1980—less if shelter costs less than $35 monthly.

[3] State decides benefit on a case-by-case basis.

[4] Payment level for Hennepin County. State has 10 geographic payment levels.

[5] State has two geographic payment levels—highest levels are shown in table. Sum paid in King, Pierce, Kitsap, Snohomish, and Thurston Counties.

[6] Among the States with a payment Illinois is not classified. Connecticut is classified as having a payment above the median.

Source: Office of Research and Statistics and Office of Supplemental Security Income, Social Security Administration.

APPENDIX

ORGANIZATIONS SUPPORTING THE FOLLOWING SSI REFORM LEGISLATION:

H.R. 360, 361, 866, 867, 868

AMERICAN ASSOCIATION OF RETIRED PERSONS

INSTITUTE FOR THE PUERTO RICAN-HISPANIC ELDERLY

NATIONAL ALLIANCE FOR THE MENTALLY ILL

NATIONAL COUNCIL OF SENIOR CITIZENS

NATIONAL COUNCIL ON THE AGING

NATIONAL MENTAL HEALTH ASSOCIATION

OLDER WOMEN'S LEAGUE

UNITED JEWISH FEDERATION/FEDERATION OF JEWISH PHILANTHROPIES OF NEW YORK

BACKGROUND ON H.R. 360:

LEGISLATION TO REFORM THE SSI ASSET TEST

Introduced by Rep. Roybal and Rep. Downey on January 3, 1989

Description:

Amends Title XVI of the Social Security Act to raise the Supplemental Security Income (SSI) asset resource limits to $4,200 for an individual and $6,300 for a couple, and indexes any future increases to the Consumer Price Index.

Background:

When SSI was first established in 1974, the asset standard for an individual living alone was $1,500; for a couple, $2,250. In 1989, these levels are $2,000 for an individual and $3,000 for a couple. No further increases in the asset level are presently scheduled. The $4,200 asset test for an individual and $6,300 for a couple in this bill are the levels which would exist if the 1974 levels had kept pace with inflation.

In real dollar terms, these asset levels have been cut virtually in half by inflation. The American Association of Retired Persons estimates that over 100,000 low income elderly Americans, who otherwise would have been eligible for SSI, no longer are because of the erosion of this asset test standard. What is more, since the asset test is not tied to annual increases in the Consumer Price Index, low income individuals will systematically become ineligible for SSI each year as inflation increases.

Assests are defined as things one owns, such as real estate, personal belongings, a car, savings and checking accounts, cash, stocks, bonds, etc. Some assets are not counted: the home one lives in, household goods and personal effects with a limit of $2,000 in equity value; $4,500 of the current market value of a car; burial plots; and a maximum of $1,500 for burial funds for an individual and a like amount for one's spouse.

Cost Estimates

Informal CBO cost estimates provided to the Select Committee on Aging indicate that the total costs to the Federal government would be about $45 million in FY 90. (Note: the jump in the cost estimate from 1990 to 1991 is based on the assumption that it will take a while to phase in the legislation and for people to learn about the asset level changes so that they come on the program).

(by fiscal years; in millions of dollars)

	1990	1991	1992	1993	1994
OUTLAYS					
SSI	35	85	115	115	115
Medicaid	10	20	30	35	35
Food Stamps	*	-5	-5	-5	-5
TOTAL OUTLAYS	45	100	140	145	145

* Less than $500,000

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BACKGROUND ON H.R. 361: LEGISLATION TO RAISE FEDERAL SSI BENEFIT LEVEL TO POVERTY

Introduced by Rep. Roybal and Rep. Downey on January 3, 1989

Description

Amends Title XVI of the Social Security Act to gradually raise the Federal SSI benefit payment to the poverty line over a three year period.

Benefit Amounts Under H.R. 361:

Individuals

	Yearly Benefit	Monthly Benefit
1989	$4,416	$368
Jan. 1, 1990	$5,244	$437
Jan. 1, 1991	$6,072	$506
Jan. 1, 1992 (est.)	$6,900	$575

Couples

	Yearly Benefit	Monthly Benefit
1989	$6,636	$553
Jan. 1, 1990	$7,504	$625
Jan. 1, 1991	$8,368	$697
Jan. 1, 1992 (est.)	$9,240	$770

Background

In 1987, there were 4.4 million low income individuals on SSI. Approximately 1/3, or 1.45 million were eligible on the basis of age. The amount of the monthly Federal SSI payment is determined by the recipient's countable income, living arrangement, and marital status. The Federal SSI benefit standard is the floor of income assured by the program for people with no countable income. Actual benefit payments are computed by subtracting the individual's/couple's countable income from the benefit standard. The Federal SSI benefit standard is indexed annually to the CPI by the same percentage as Social Security benefits.

The 1989 Federal benefit level for individuals ($368/month) is approximately 75% of the Federal poverty level and the benefit for couples ($553/month) is approximately 83% of the poverty level. While States are permitted to supplement the Federal SSI benefit, only about half provide a general supplementation to those on SSI, and only 5 provide enough of a supplement to raise the benefit to the poverty level. Hearings before the Select Committee on Aging reveal that the median State supplement is about $36 per month, or only about $9 per week. Despite the existence of SSI, many elderly, blind and disabled persons struggle in economic difficulty.

Costs

Informal estimates by the Congressional Budget Office indicate that in 1990 the total cost to the Federal government would be around $2 billion; in 1991, around $5 - $6 billion; and in 1992 - 1994 when all eligible participants would be brought up to the poverty level, around $8 - $9 billion.

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H.R. 866, 867, 868:
Introduced originally by Matsui, Downey, Miller (CA), and Roybal

HIGHLIGHTS OF SSI LEGISLATION

A. Major Benefit and Resource Changes

1. Increase SSI to poverty level
2. Increase resource limit to equal value in 1974
3. Establish Permanent SSI Outreach Program for Adults and Children
4. Increase in Benefits for Aged and Disabled Persons Being Cared for in Other's Home or Receiving Housing or Other In-Kind Income
    a. Individuals living in low income households would have only actual value of in-kind assistance counted as income instead of automatic one-third reduction in benefits.
    b. Aged and disabled persons who are ineligible for SSI because of in-kind income from living with others or receiving below cost housing, would, nevertheless be treated as SSI recipients in determining eligibility for Medicaid.

B. Disability Criteria for Children

1. Clarify that there must be an individualized assessment of each child, including consideration of functional limitations.
2. Children, ages 3 years and younger, will be presumed disabled if the child has a congenital or genetic impairment which is probable to be found disabling if tests existed which permitted testing of the young child.

C. Protection Against Loss of Medicaid for SSI Disabled Persons When Eligible for Social Security

1. Continued Medicaid for disabled persons when eligible for Social Security early retirement or spouse benefits at age 62.
2. Continued Medicaid for disabled who lost SSI/Medicaid prior to July 1987, when they became eligible for Social Security disabled adult children benefits.
3. Continued Medicaid eligibility determinations to be provided by Social Security Administration for early retirees, spouses, and disabled widowers.

D. Technical Amendments to SSI Income and Resource Eligibility Criteria for Adults and Children

1. Worker's compensation and unemployment compensation to be treated as earned income with $65 plus 1/2 remaining disregarded rather than as unearned income with only $20 disregard.

2. Parent's income deemed to disabled children which fluctuates in the amount of monthly earned income (resulting from bi-weekly pay periods) would be averaged over a year to monthly average if such averaging would prevent loss of SSI and Medicaid in certain months.

3. Interest income of $120 a year (increasing by $12 a year) would be disregarded in determining SSI benefits.

4. Life insurance policies (which have cash value) would not have their cash value counted if their face value is $2500 or less instead of the current $1500 limit. Allowable burial accounts would also be increased from $1500 to $2500.

5. Members of an SSI eligible couple would each be treated as individuals after one month of living apart instead of six months.

6. Gifts to aged, blind or disabled individuals in the form of commercial transportation tickets would not be counted as income.

7. Property essential for self-support would not be counted as a resource. Only income from such property is to be counted in determining eligibility.

NEWS

Select Committee on Aging

U.S. House of Representatives

EDWARD R. ROYBAL, Chairman
300 New Jersey Ave., S.E., Room 712
Washington, D.C. 20515
202/226-3375

FOR RELEASE
January 11, 1989

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ROYBAL AND DOWNEY SEEK MAJOR REFORM OF FEDERAL PROGRAM TO ASSIST POOR AGED, BLIND, AND DISABLED AMERICANS

JOINTLY SPONSOR LEGISLATION - H.R. 360 & 361 - TO MAKE SUPPLEMENTAL SECURITY INCOME PROGRAM MORE HUMANE

Washington, D.C., January 11 - California Congressman Edward R. Roybal, Chairman of the House Select Committee on Aging and its Subcommittee on Retirement Income and Employment, and New York Congressman Thomas J. Downey, Acting Chairman of the Aging Committee's Human Service Subcommittee and the Acting Chairman of the Subcommittee on Public Assistance of the Ways and Means Committee, today announced the initiation of a joint effort to seek major reform of the Federal program designed to provide a minimum "safety net" income for the Nation's poorest elderly, blind, and disabled citizens.

"Based on testimony and information provided to the Aging Committee over the past year and a half," Roybal declared, "we have become gravely concerned about the inadequate benefit levels, great gaps in service, and outdated eligibility requirements which characterize the SSI (Supplemental Security Income) program."

Federally financed through general revenues and administered by the Social Security Administration, the Supplemental Security Income (SSI) program is designed to provide a nationally uniform minimum income for the aged, blind, and disabled, with uniform asset and income standards to determine eligibility. When enacted, it replaced a highly decentralized maze of state-operated Old Age Assistance programs. Since it began operation in 1974, however, there has been little change in eligibility criteria, benefit levels, or target populations.

"The SSI program today reflects the hoax that the so called safety net has become for our poorest people. Today almost half of the elderly poor who are eligible for SSI do not receive it. Meanwhile, for the estimated 4.4 million of all ages who do receive it, they are provided with an income that does not even equal the poverty level," Downey said.

Roybal and Downey also pointed out that the asset eligibility test has been cut in half in real dollar terms since the program's inception in 1974 because it has not kept pace with inflation. Testimony before the Aging Committee by the American Association of Retired Persons indicates that over 100,000 low income elderly Americans, who otherwise would have been eligible for SSI, no longer are because of the erosion of this asset test standard.

To address these issues, Roybal and Downey announced that they had jointly introduced two pieces of major SSI reform legislation. The first, H.R. 360 restores the SSI asset eligibility test to the same inflation-adjusted dollar equivalent as when the program was first enacted, and indexes any future increases to the Consumer Price Index. The second, H.R. 361 amends title XVI of the Social Security Act to gradually raise the Federal SSI benefit payment to the poverty line by January 1, 1992.

"Passage of these bills is critical if we - as a Nation - are serious about providing an adequate safety net for the poorest of our citizens," Roybal said. "It is unconscionable for the Federal government to establish a poverty guideline which is designed to measure the minimum income needed to meet basic nutritional and daily living requirements, while then establishing a benefit which only provides three-fourths of this income. This forces our most vulnerable citizens to make impossible decisions between receiving adequate nutrition, health care, heating, or other necessities."

"It is obvious that the SSI program is in desperate need of reform. The Roybal-Downey bills offer a two-pronged approach by raising the benefit to the poverty level and liberalizing the SSI asset test to allow more eligible poor to enroll in SSI instead of being removed. The commitment to being a kinder and gentler nation may well be measured by the extent to which these SSI reform bills gain bi-partisan support," Downey said.

NEWS

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Select Committee on Aging

U.S. House of Representatives

FOR RELEASE
February 10, 1989

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ROYBAL EXPANDS DRIVE TO REVITALIZE FEDERAL ASSISTANCE TO POOR AGED, BLIND, AND DISABLED AMERICANS

JOINS REPRESENTATIVES MATSUI, DOWNEY, AND MILLER IN INTRODUCING COMPREHENSIVE SSI REFORM LEGISLATION:

H.R. 866, 867, & 868

Washington, D.C., February 10 — California Congressman Edward R. Roybal, Chairman of the Select Committee on Aging and its Subcommittee on Retirement Income and Employment, this week joined with California Congressman Robert Matsui, Member of the House Ways and Means Committee, New York Congressman Thomas Downey, Acting Chairman of the Ways and Means Committee's Subcommittee on Human Resources, and California Congressman George Miller, Chairman of the Select Committee on Children, Youth and Families, in introducing a comprehensive legislative package to reform the Supplemental Security Income (SSI) program.

"The Federal program designed to guarantee an adequate minimum income to our poorest elderly, blind, and disabled citizens is failing due to National neglect," Roybal declared. "The time has come for the Federal government and the States to come together and more humanely assist those who are unable to join the workforce. Twelve dollars a day does not a 'kinder, gentler' Nation make."

Federally financed through general revenues and administered by the Social Security Administration, the Supplemental Security Income program, or SSI, is designed to provide a nationally uniform minimum income for the aged, blind, and disabled, with uniform asset and income standards to determine who is eligible. The maximum Federal SSI benefit for an individual is presently $368/month, or about $12/day. While States are permitted to supplement this amount, only two out of five SSI recipients get a State supplement, with the median benefit in 1987 being $36/month or about a dollar a day.

"Earlier this Congress, Representative Downey and I introduced two major pieces of legislation," Roybal noted. "The first, H.R. 360, adjusts the SSI asset eligibility test to keep pace with inflation. The second, H.R. 361, gradually raises the Federal SSI payment to the poverty line by 1992."

"This effort has now been expanded to reform other major gaps in coverage and assistance through the introduction of three comprehensive bills - H.R. 866, H.R. 867, and H.R. 868," Roybal said. "Given the importance of SSI to all generations of Americans, I am glad to be able to join in original cosponsorship of this effort with the Chairman of the Select Committee on Children Youth and Families, as well as two key members of the Ways and Means Committee's Subcommittee on Human Resources, which has legislative jurisdiction over this program."

Among the major provisions of H.R. 866 are the establishment of a permanent SSI outreach program for adults and children, as well as a requirement that an individual be allowed to live with another person and receive in-kind assistance without losing SSI eligibility for Medicaid.

H.R. 867 corrects inconsistencies in current law regarding treatment of unemployment compensation, interest and dividend income, life insurance, and burial accounts.

H.R. 868 assures that SSI is fairer and more responsive to poor disabled children by reforming the definition of disabled children to comply with current medical practices, and by correcting certain inequities in the treatment of a family's income and resources in determining program eligibility.

"It is tragic that children across the country are dying before determinations can be made that they are indeed disabled, and that half of the elderly who are eligible for SSI are not on the program because they do not know about it or face other difficulties," Roybal concluded. "I urge a strong commitment from the President, the Congress and State officials to eliminate this National tragedy and join us in enacting SSI reform."

NEWS

Select Committee on Aging

U.S. House of Representatives

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FOR RELEASE
March 2, 1989

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ROYBAL AND DOWNEY TO CONVENE JOINT AGING COMMITTEE AND WAYS AND MEANS SUBCOMMITTEE HEARING ON SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

NINETY-SEVEN YEAR-OLD RECIPIENT AMONG THOSE TO TESTIFY ON ADEQUACY OF MAXIMUM FEDERAL "SAFETY NET" BENEFIT TO AGED, BLIND, AND DISABLED INDIVIDUALS - $12/DAY

Washington, D.C., March 2, 1989 — California Congressman Edward R. Roybal, Chairman of the House Select Committee on Aging, and New York Congressman Thomas J. Downey, Acting Chairman of the Subcommittee on Human Resources of the House Committee on Ways and Means, today announced that they will hold a joint hearing on the Supplemental Security Income (SSI) program. **The hearing will convene on Thursday, March 2, 1989, in room 1100 Longworth House Office Building at 1:00 PM.**

"The Federal program designed to guarantee an adequate minimum "safety net" income to our poorest elderly, blind, and disabled citizens is failing due to National neglect," Roybal said. "The time has come for the Federal government and the States to come together and more humanely assist those who are unable to join the workforce. Twelve dollars a day does not a 'kinder, gentler' Nation make."

Federally financed through general revenues and administered by the Social Security Administration, the SSI program is designed to provide a nationally uniform minimum income for the aged, blind, and disabled, with uniform asset and income standards to determine who is eligible. The maximum Federal SSI benefit for an individual is presently $368/month, or about $12/day. While States are permitted to supplement this amount, only two out of five SSI recipients receive a State supplement, with the median benefit in 1988 being about $36/month, or a little over a $1/day.

"Two out of five SSI recipients who qualify on the basis of age are 80 years old or over," Roybal noted. "I'm particularly interested in hearing how a 97 year-old woman living alone - and thousands of other frail older Americans like her - are able to meet daily living expenses on a combination of Social Security and SSI which totals around $370/month. Information provided to my Aging Commitee indicates that Miss Brown-Bey and other frail older Americans like her often have to make difficult choices between eating and paying utility bills."

Other testimony is expected to focus on how well SSI addresses the needs of disabled children and their families. Recent data indicate that only one-fourth of all totally disabled children living in families below the poverty level are enrolled in the SSI program. Half of all adult disabled persons living independently are impoverished.

"Given the intergenerational importance of SSI, I commend Acting Chairman Downey for calling for this important joint hearing," Roybal said. "It is my hope that the testimony will provide the Congress with direction as to how a key component of the Nation's safety net program can more adequately assist its most vulnerable citizens."

INVITED WITNESSES

Ms. Blanche Brown-Bey, Indianapolis, IN; 97 year-old SSI recipient testifying on behalf of the Villers Advocacy Associates who will describe living on the Federal benefit standard.

Mr. William Shelton, Knoxville, TN; will discuss the adequacy of the SSI program to meet the needs of disabled children.

Dr. Elizabeth Boggs, Hampton, NJ; will discuss her experiences as the parent of a developmentally disabled child and as the past President of the Association for Retarded Citizens regarding the SSI program and disabled individuals and their families.

Mr. Ronald Pollack, Executive Director, the Villers Foundation; will provide a summary overview of current SSI issues and possible directions for SSI reform.

The Honorable Dorcas Hardy, Commissioner, Social Security Administration; will provide the Administration's perspective on the SSI program.

Chairman Roybal. The committee will come to order. Ladies and gentlemen, I would like to, first of all, commend the acting chairman, Congressman Downey, for his leadership in calling for this joint hearing on the SSI program. It is my hope that today's testimony will provide the Congress with positive suggestions for improving this program which is so vital to the well-being of 4½ million elderly, blind, and disabled Americans.

While SSI is intended to provide a safety net income for the most vulnerable of our citizens, previous hearings before the Aging Committee have indicated that it is, in fact, characterized by serious deficiencies. Among the most serious of these deficiencies is the inadequate benefit level.

The maximum Federal SSI benefit for the qualified individual is presently $368 per month, or about $12 per day. This is less than 75 percent of the poverty level.

While States are permitted to supplement this amount, only two out of five SSI recipients get a State supplement. The median State benefit in 1988 was about $36 per month, or just a little over $1 per day.

Now I believe it is crucial to keep in mind the nature of the population that is served by SSI. They are the disabled, who by definition are unable to work due to physical or mental impairment. They are also the elderly poor, two out of five of whom are over 80 years old. And they are the blind, many of whom are elderly or unable to find suitable employment. These are the Americans that we are requiring to live on $12 or $13 per day.

I hope this matter and other SSI issues can be addressed during this session of the Congress.

We are very fortunate to have with us today a knowledgeable panel of witnesses who can describe their own firsthand experience with the SSI program. I would particularly like to commend and thank Ms. Blanche Brown-Bey for her willingness to come all the way from Indianapolis to tell her story to the committee. I greatly admire her unselfishness and concern for others. When asked if she would be willing to make such a long trip out here, she told my staff that she would do whatever she could if it might help others in her situation.

I look forward to the testimony of all the witnesses and hope the Congress and the President can make good on Ms. Bey's wish, that we do a better job of helping not only her but other individuals like her throughout the United States.

[The opening statement of Chairman Roybal follows:]

Opening Statement

Edward R. Roybal, Chairman

Select Committee on Aging
U.S. House of Representatives

Before A Joint Hearing With
The Subcommittee on Human Resources
Committee on Ways and Means

"The Supplemental Security Income (SSI) Program"

March 2, 1989

Good afternoon, Ladies and Gentlemen. I would like to commend Acting Chairman Downey of the Ways and Means Subcommittee on Human Resources for his leadership in calling for this important hearing on the SSI program. The purpose of this hearing is to examine whether SSI is adequately assisting our low income elderly, blind, and disabled citizens across the generations. It is my sincere hope that today's testimony will provide the Congress with positive suggestions for improving this program which is so vital to the health and well-being of more than 4.3 million Americans.

The SSI program provides benefits to low income elderly (age 65 and above), disabled, or blind individuals who satisfy both income and asset eligibility requirements. It is wholly federally financed by general revenues and is administered by the Social Security Administration. The amount of the monthly Federal SSI payment is determined by the recipient's countable income, living arrangements, and marital status. Actual benefit payments are computed by subtracting the individual's or couple's countable income from the benefit standard. As of September, 1988, about 4.3 million individuals receive SSI. Approximately one-third, or 1.4 million recipients are eligible on the basis of age; over half, 2.9 million are eligible on the basis of disability; and 2%, or 82,740 are eligible on the basis of blindness (see chart on page 3).

I am greatly concerned that while SSI is intended to provide a "safety net" income of support for the poorest and most vulnerable of our elderly, blind, and disabled citizens, previous hearings before my Aging Committee indicate that it is in fact characterized by inadequate benefit levels, large gaps in service, insufficient outreach activities, and overly rigid eligibility requirements.

Among the most serious of these problems is the inadequacy of the benefit standard. The maximum Federal SSI benefit for a qualified individual is presently $368 per month, or about $12 per day. This is less than 75% of the poverty level.

While States are permitted to supplement this amount, **only two out of five SSI recipients receive a State supplement. The median State benefit in 1988 was about $36 per month, or a little over one dollar per day.**

It is crucial that we keep in mind the nature of the population that SSI is meant to serve. They are the disabled, who by definition are unable to work due to a physical or mental impairment. They are infants. They are the elderly poor - two out of five of whom are over 80 years of age. And they are the blind, many of whom are elderly or are otherwise unable to obtain suitable employment. These are the Americans that we are requiring to live on twelve or thirteen dollars per day.

I firmly believe that we can - and must - do a better job of providing a more humane minimum income for our poorest and most vulnerable citizens. That is why I jointly introduced legislation at the beginning of this session with Acting Chairman Downey - H.R. 361 - to gradually raise the Federal benefit standard to the poverty level by 1991. This legislation currently has the bipartisan cosponsorship of over 40 Members of the House and has the support of a large variety of national organizations, including: the American Association of Retired Persons, the Institute for the Puerto Rican-Hispanic Elderly, the National Alliance for the Mentally Ill, the National Caucus and Center on the Black Aged, the National Council of Senior Citizens, the National Council on the Aging, the National Mental Health Association, the Older Women's League, the United Jewish Federation/Federation of Jewish Philanthropies of New York, and the Viller Advocacy Associates. I believe the testimony we receive today will provide further evidence that raising the Federal SSI benefit standard to the poverty level should be a major priority of this session of Congress.

Another serious problem is that since the program was first established in 1974, the asset eligibility standard has been cut virtually in half in real dollar terms because it has not kept pace with inflation (see attached chart). Consequently, a substantial number of needy Americans who otherwise would be eligible no longer are because of the erosion of this asset test standard. That is why I have also joined with Acting Chairman Downey in introducing H.R. 360 which raises the asset test to the level it would be had it been adjusted according to the Consumer Price Index (CPI) since 1974. Additionally, the legislation indexes any future increases to the CPI.

Numerous studies have documented that the SSI program only reaches about half of those elderly individuals who are eligible. For a Nation which has such a wealth of communication resources, we are failing miserably when one of the major reasons given for nonparticipation in the SSI program is that a majority of the eligible population has never heard of it.

Many others who may have heard of SSI often cannot complete the difficult application process, or face language barriers which make applying difficult - if not impossible. Spanish-speaking applicants, for instance, often must provide their own interpreter at the local SSA office in order to try to get through the application process.

While the Social Security Administration is required to initiate outreach activities, previous testimony before the Aging Committee indicates that little time or resources are devoted to this effort. **This situation is extremely unfortunate as there is strong evidence that outreach can be very successful in adding new applicants to the program.** For instance, in 1988, the American Association of Retired Persons with support from the Commonwealth Fund Commission on Elderly People Living Alone, formed a coalition of approximately 40-50 agencies to assist with a five month demonstration SSI project. The project was conducted in three demonstration sites - El Paso, Texas; Pittsburgh, Pennsylvania; and Oklahoma City, Oklahoma - and was designed to serve as a model for similar outreach efforts which might be implemented throughout the country.

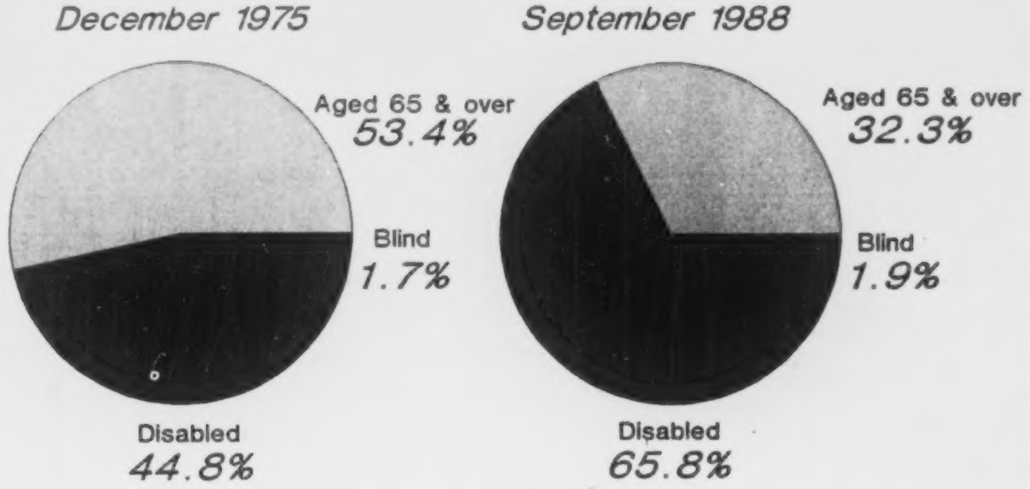
Together, the three sites processed an average of 97 percent more SSI applicants per month after the outreach project began, and resulted in 58% more awards being made. I believe it is crucial that more permanent public/private partnerships such as these be funded and established so that effective outreach efforts are operating in every part of the country.

We are very fortunate to have with us a very knowledgeable panel of witnesses who can describe their own firsthand experiences with the program. I would particularly like to commend and thank Miss Blanche Brown-Bey for her willingness to come from Indianapolis to tell her story to the Committee. I greatly admire her unselfishness and concern for others. When asked if she would be willing to make such a long trip, she told my staff that she would do whatever she could if it might help others in her situation.

Other testimony is expected to focus on how well SSI addresses the needs of disabled children and their families. It is tragic that, due to flaws in the definition of childhood disability, children across the country are dying before determinations can be made that they are indeed disabled. Recent data indicate that only one-fourth of all totally disabled children living in families below the poverty level are enrolled in SSI. What is more, half of all adult disabled persons living independently are impoverished.

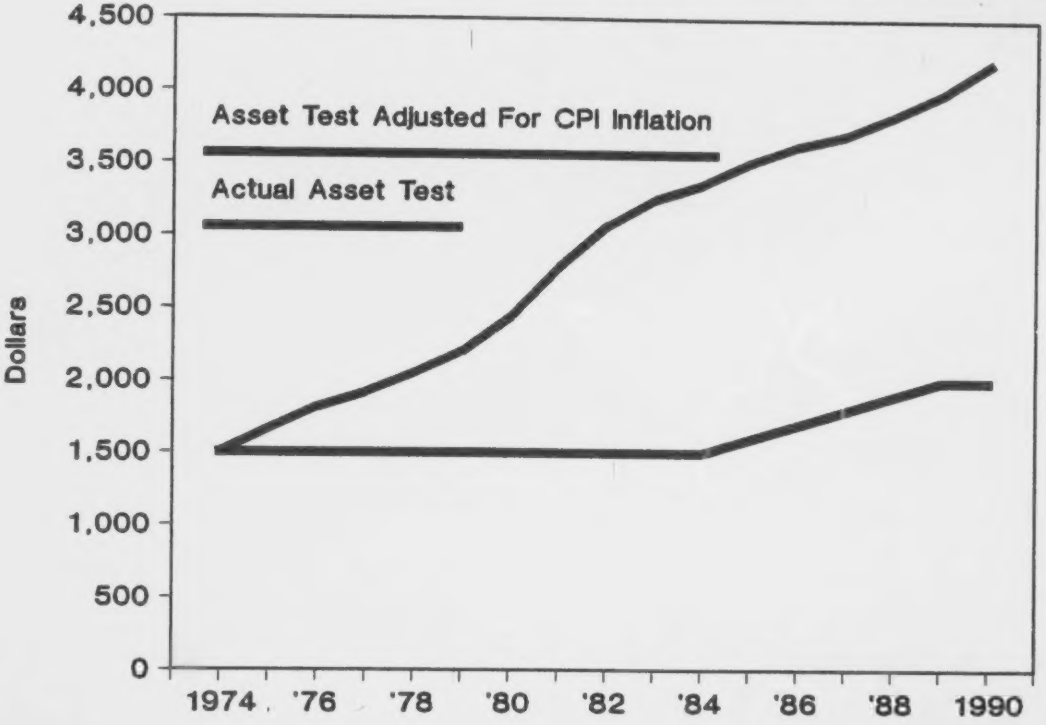
I look forward to the testimony of all the witnesses and hope the Congress and the President can make good on Miss Brown-Bey's wish that we do a better job of providing a more humane and compassionate minimum income for her and other individuals like her.

SSI: Percentage Distribution of Persons Receiving SSI Payments, by Reason for Eligibility: December 1975 and September 1988

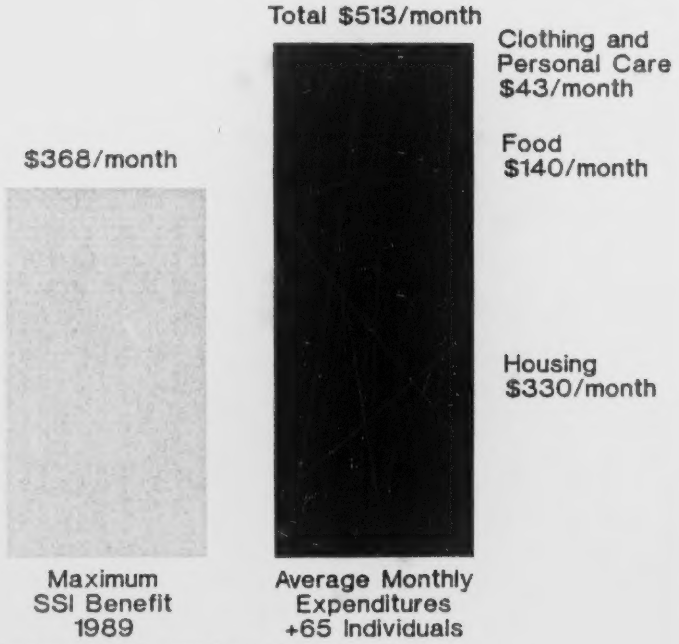


Source: Ways and Means Committee

History of SSI Asset Test Levels For Individuals
Actual Levels Compared With Inflation Adjusted Levels



1989 Federal SSI Benefit Level Compared With Average Monthly Expenditures Of Individuals Age 65 and Over



Source: Bureau of Labor Statistics - Consumer Expenditure Survey - 1986 Figures Adjusted For Inflation

Chairman **Roybal**. The Chair will recognize the acting chairman, Congressman Downey, for an opening statement. Then we are going to ask that all those who have statements include those for the record because Ms. Bey wishes to testify as soon as possible and then leave because she must make the trip back to Indianapolis.

The Chair now recognizes Congressman Downey.

Acting Chairman **Downey**. Thank you, Mr. Chairman. It would be completely inappropriate if I and the other members of this committee did not pay homage to you and to the work that you have done in bringing SSI and the problems attendant with some aspects of the program to our attention. I am privileged now to be acting chairman of the Ways and Means Subcommittee that has jurisdiction over this matter. It is as a result of the work that you have done and the hearings that you have held that have pushed us as far as we have gone.

We convene this afternoon's hearing on the supplemental security income program at an important crossroads. Nearly 15 years after its creation, the SSI program has become one of the mainstays of our basic social safety net, helping 4.4 million aged, blind and disabled Americans survive. However, it is also a time when the population served by SSI is changing.

Although the number of people receiving SSI has increased only slightly since 1975, the 4.4 million people served today are very different from their counterparts in 1975. There are fewer elderly recipients and there are many more disabled individuals receiving supplemental security income. The disabled and the blind population is also much younger than it was 15 years ago and the nature of their disabilities has changed.

More than half of disabled SSI recipients between the ages of 22 and 65 are mentally disabled. Many of them must live with relatives or need special housing arrangements. Severely disabled children who 20 years ago might not have survived are now being cared for by their families. For these children, there is growing evidence that overly restrictive adult SSI disability criteria that simply do not fit the circumstances of the children are denying them financial and medical assistance they desperately need.

Our hearing today starts the process of examining the adequacy of the SSI program. It is a process that I am particularly pleased to begin with Congressman Roybal, the respected chairman of the Aging Committee. The time for us has come to examine the adequacy of the SSI benefit level, to consider the special needs of the recipients who must rely on others for their care, and to determine what changes are needed to accommodate severely disabled children.

I look forward to the testimony of the panel.

Chairman **Roybal**. Thank you, Mr. Downey.

[Additional opening statements and attachments follow:]

Matthew J. Rinaldo

Opening Remarks of
Congressman Matthew J. Rinaldo
for the
Supplemental Security Income (SSI) Hearing

Mr. Chairman:

I want to commend you for holding today's hearing on Supplemental Security Income (SSI). I welcome the opportunity to examine what has been called the nation's best kept secret in its arsenal of programs to help the blind, aged, and disabled.

When Congress originally authorized the SSI program, it was designed to reach out to members of society who were unable to help themselves. Individuals qualified for benefits only by meeting the strictest and most severe of income and asset standards and were provided with a lifeline of support and services.

SSI still provides that safety net of protection for the poorest and most vulnerable members of society, but studies now show that it is not reaching everyone it was designed to help. In fact, it appears that only about half those eligible for benefits actually participate in the program.

Why such a low participation rate? These same studies reveal an almost complete lack of public information exists about SSI. People are unfamiliar with the program and what it provides, they don't know how to apply for benefits, and some aren't even aware that SSI exists.

Last year almost 4.5 million people participated in the SSI program. In my own state of New Jersey almost 100,000 people drew benefits. Still, these reports indicate that we're only seeing the tip of the iceberg when it comes to people who need assistance. Clearly more must be done to spread the word about SSI.

Today, as in previous hearings on SSI, we will hear from those who must deal with the program first hand. We will hear about inadequate benefit levels, strictly rigid income and asset requirements, and inadequate outreach efforts.

To begin with, benefit levels are low: in fact, they are below the poverty threshold. The maximum benefit derived from SSI amounts to $368 a month or about $12 a day.

Moreover, the lack of knowledge about the program is disturbing.

In a country with the most modern, up-to-date and effective media resources in the world we should do all we can to disseminate information about SSI to our neediest citizens.

SSI can be the vital lifeline it was intended to be. It can provide needed assistance to the poor, elderly and disabled. But it must change. We cannot expect to meet the challenges of the 90's using formulas and ratios designed and developed in the 70's.

I am hopeful that this hearing will provide an added impetus to the SSI reform movement, and that it will help make SSI the safety net it was designed to be.

Record

REMARKS OF THE HONORABLE CLAUDINE SCHNEIDER

March 2, 1989

SELECT COMMITTEE ON AGING

HEARING ON SUPPLEMENTAL SECURITY INCOME REFORM

Chairman Roybal and Chairman Downey, I am pleased that you have called this hearing to examine the Supplemental Security Income (SSI) program. This is a vital program which serves the most vulnerable of our society -- the aged, poor, blind and disabled. However, because eligibility limits are substantially below the poverty level, many of the poor elderly are excluded from receiving payments. And while people receiving SSI payments number in the millions, there are many more who are eligible and who don't receive payments. In addition, the asset standard test, initiated in 1974, has not kept pace with inflation and the rise in the consumer price index. This hearing is important for addressing these issues, as well as others which affect the elderly poor.

I would like to point out that most of the vulnerable elderly we are discussing today are women. Three out of four of the elderly poor are older women. If you include the near poor, that figure jumps to one out of three! These women are more likely to be living alone and supporting themselve solely witn their Social Security benefits. Because women have fewer years in the workforce and lower paid jobs when employed, many retired women do not have pensions. Only 20% of older women collect pensions!

Clearly, older women are hit hard when the programs that are designed to help the needy are underfunded and underutilized. The current SSI maximum payment is $368 per month, while the Federal poverty level is $490 per month. The Consumer Expenditure Survey of the Bureau of Labor Statistics has found that the average monthly expenditures of the elderly is $513 per month. The SSI maximum payment is substantially below the poverty level, a level established ironically by the same government that administers the SSI program. This sets up situations where our elderly are forced to choose between paying utility bills and buying groceries. We, still in the workforce, do not have to face such choices and I am sure that we do not look forward to that kind of decision making when we retire. As a responsible nation and government, we need to make sure that all of the vulnerable and needy are assured a consistent standard of living.

The SSI program is very important for the 16,000 Rhode Island recipients of SSI. In fact, Rhode Island is one of the 26 states that supplements the Federal payment with a state benefit.

In an effort to address these problems with the SSI program, my colleagues Mr. Roybal and Mr. Downey have introduced legislation which will reform SSI. I have cosponsored two bills, the SSI Asset Reform Act of 1989 and the SSI Benefit Level Reform Act of 1989. In addition, one of my priorities is the Family and Medical Leave Act which will guarantee that workers who need to take time off from work for childbearing or for care of a dependent will be able to return to their jobs. This is especially significant for women who traditionally face lower wages and lower pensions because of employment breaks caused by maternity leave and child rearing responsibilities. Pension portability, pay equity and long term health care are other issues I am working on which impact on the status of older women.

Statement of
THE HONORABLE ROBERT T. MATSUI
THIRD DISTRICT OF CALIFORNIA
before
THE HUMAN RESOURCES SUBCOMMITTEE
WAYS AND MEANS COMMITTEE
and
THE SELECT COMMITTEE ON AGING
on
THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

Chairman Downey and Chairman Roybal, I want to thank you for holding this very important hearing on the Supplemental Security Income (SSI) Program. I also want to thank you and Congressman Miller for co-sponsoring with me our three bills, H.R. 866, 867 and 868, which would make the SSI program fairer and more responsive to the truly needy it is intended to serve.

SSI - A Failed Guarantee Against Poverty

Contrary to popular perception, poverty among elderly and disabled Americans not only persists, but is growing in our nation. Three and one-half million elderly persons -- about 13 percent of all persons age 65 and older -- have incomes below the poverty line. Poverty rates for disabled adults are even higher. It is estimated that more than one third of disabled adults have incomes below the poverty line and half of the disabled persons living independently are impoverished. Perhaps the most shocking statistic is that some 13 million children in this country -- more than 20% of U.S. children -- are poor. These children born in poverty are 50% more likely to have a disability.

Congress enacted the SSI program in 1972 to guarantee a minimum level of cash income to these senior citizens, disabled adults, and disabled children. However, today that guarantee has failed.

Although the program's concept and structure are basically sound, the current level of federal assistance does not provide recipients with an income that even brings them up to the poverty line. The maximum federal SSI benefit standard for single persons is only about 75 percent of the poverty level ($368 a month for an individual and $553 for a couple). In addition, the SSI allowable assets limit is very low and has not been adjusted to keep up with inflation since 1972. As a result, many individuals who are truly impoverished are excluded from the SSI program.

SSI recipients who choose to live with families and friends are treated even more unfairly by the SSI program. Over 250,000 aged and disabled individuals receive SSI on the basis of a Federal SSI benefit standard of only $245 a month because they are living with family or friends. Present SSI law assumes that their needs are less because they are receiving in-kind assistance even though their needs are great because of their disability or frail condition. This situation often involves parents caring for their adult mentally retarded son or daughter who is not capable of living by themselves. In many cases, where the adult disabled child receives some Social Security on their elderly parents earnings record, that income makes them totally ineligible for any SSI or Medicaid.

Adding to the program's problems are a number of technical eligibility rule "glitches", each affecting certain specific subgroups of SSI recipients, which collectively create a great deal of suffering and misfortune for many elderly and disabled persons. Correcting each glitch is very important to those aged, blind, or disabled individuals who would retain eligibility for SSI if it were not for the unfair and often unintended consequences of current law.

Some elderly and disabled persons do not participate in SSI because their incomes are above the SSI benefit standard. Others do not qualify because their countable assets are greater than the restrictive allowable asset limit. But even with these restrictive eligibility guidelines, a large number of potential SSI beneficiaries do not participate because they do not know the program exists. One study reports that 45 percent of eligible persons who did not participate simply were unaware of its existence.

SSI and Children with Disabilities

The SSI program was also intended to help the families of disabled children. Children in low-income families with disabilities of "comparable severity" to adults are eligible for SSI benefits. While the case payment is important to these low-income families, the Medicaid benefit that SSI eligibility carries with it in almost all states is critical. It is often the only regular source of health care essential to stabilizing and ameliorating the child's condition. Yet despite the obvious benefits of the SSI program for poor families with disabled children, the majority of these children are not enrolled in the program. Data from a National Health Interview Survey indicates that only a quarter of all totally disabled children living at home below the poverty line are enrolled in the SSI program.

Revitalizing the SSI Program

Congressman Downey, Congressman Miller, Congressman Roybal and I have introduced three bills which address all of the problems I have described with the current SSI program. H.R. 866, the "SSI Benefit Improvements Amendments of 1989", would raise the SSI Federal benefit standard level to the poverty line over three years and raise the asset limit to reflect inflation. It would allow a person to live with a friend or family and receive in-kind assistance without losing SSI eligibility for purposes of Medicaid. It also would require that the Social Security Administration establish a permanent SSI outreach program for both adults and children.

H.R. 867, the "SSI Technical Amendments of 1989", would correct glitches in current law including treatment of unemployment compensation, weekly or bi-weekly income, travel tickets, income upon separation, interest and dividend income, life insurance, and burial accounts. It also would extend SSI eligibility for purposes of Medicaid eligibility in several special deserving situations.

The third bill we introduced would assure that poor disabled children do not fall through the SSI safety net. The "SSI Disabled and Blind Children Act of 1989" would reform the definition of disabled children to comport with current medical practices, and correct certain inequities in the treatment of a family's income and resources in determining the eligibility of a disabled child.

I have attached to the written copy of my statement a two-page document which "Highlights" the provisions of our three SSI bills. I would like to have these highlights included in the written record of today's hearing. Also attached for submission in the hearing record is a list of national organizations endorsing our three SSI bills.

Finally, I have also included with the written copy of my statement a newspaper article which appeared in the Sacramento, California Bee last December. The reporter, John Robin Witt, describes the hardships endured by poor seniors from my home District. More than any eloquent statement which I can present here today, I think that a glimpse of the lives of the real people who need the extra help of the SSI program better persuades all of us in Congress of the necessity of SSI reform.

Thank you Chairman Downey and Chairman Roybal for holding this hearing today which will also provide us with a glimpse of the lives of the real people we strive to help. I thank you for recognizing that members of Congress must hear not only from the administration, the advocates and the experts, but also from those people who will feel the direct impact of our legislative decisions.

National Organizations Endorsing H.R. 866, H.R. 867, H.R. 868

American Association of Retired Persons
American Academy of Child and Adolescent Psychiatry
American Association for Children's Residential Centers
American Association for Marriage and Family Therapy
American Association for Partial Hospitalization
American Association on Mental Retardation
American Occupational Therapy Association
American Diabetes Association
American Foundation for the Blind
American Psychiatric Association
Association for Retarded Citizens
Autism Society of America
Children's Defense Fund (H.R. 868)
Epilepsy Foundation of America
Family Services of America (H.R. 868)
Institute for the Puerto Rican-Hispanic Elderly
International Association of Psychosocial Rehabilitation Services
Mental Health Law Project
National Alliance for the Mentally Ill
National Council of Senior Citizens
National Council on the Aging
National Caucus and Center on Black Aged
National Mental Health Association
National Alliance for the Mentally Ill
National Association for Rights Protection and Advocacy
National Association of Developmental Disabilities Councils
National Association of Private Residential Resources
National Association of Protection and Advocacy Systems
National Association of Social Workers
National Association of State Mental Health Program Directors
National Association of State Mental Retardation Program Directors
National Council of Community Mental Health Centers
National Federation of Societies for Clinical Social Work
National Mental Health Association
Older Women's League
United Cerebral Palsy Associations, Inc.
United Jewish Federation/Federation of Jewish Philanthropies of N.Y.
United Cerebral Palsy Associations, Inc.
Villers Advocacy Associates
World Institute on Disability

HIGHLIGHTS OF SSI LEGISLATION

A. Major Benefit and Resource Changes

1. Increase SSI to poverty level
2. Increase resource limit to equal value in 1974
3. Establish Permanent SSI Outreach Program for Adults and Children
4. Increase in Benefits for Aged and Disabled Persons Being Cared for in Other's Home or Receiving Housing or Other In-Kind Income
   a. Individuals living in low income households would have only actual value of in-kind assistance counted as income instead of automatic one-third reduction in benefits.
   b. Aged and disabled persons who are ineligible for SSI because of in-kind income from living with others or receiving below cost housing, would, nevertheless be treated as SSI recipients in determining eligibility for Medicaid.

B. Disability Criteria for Children

1. Clarify that there must be an individualized assessment of each child, including consideration of functional limitations.
2. Children, ages 3 years and younger, will be presumed disabled if the child has a congenital or genetic impairment which is probable to be found disabling if tests existed which permitted testing of the young child.

C. Protection Against Loss of Medicaid for SSI Disabled Persons When Eligible for Social Security

1. Continued Medicaid for disabled persons when eligible for Social Security early retirement or spouse benefits at age 62.
2. Continued Medicaid for disabled who lost SSI/Medicaid prior to July 1987, when they became eligible for Social Security disabled adult children benefits.
3. Continued Medicaid eligibility determinations to be provided by Social Security Administration for early retirees, spouses, and disabled widowers.

D. Technical Amendments to SSI Income and Resource Eligibility Criteria for Adults and Children

1. Worker's compensation and unemployment compensation to be treated as earned income with $65 plus 1/2 remaining disregarded rather than as unearned income with only $20 disregard.

2. Parent's income deemed to disabled children which fluctuates in the amount of monthly earned income (resulting from bi-weekly pay periods) would be averaged over a year to monthly average if such averaging would prevent loss of SSI and Medicaid in certain months.

3. Interest income of $120 a year (increasing by $12 a year) would be disregarded in determining SSI benefits.

4. Life insurance policies (which have cash value) would not have their cash value counted if their face value is $2500 or less instead of the current $1500 limit. Allowable burial accounts would also be increased from $1500 to $2500.

5. Members of an SSI eligible couple would each be treated as individuals after one month of living apart instead of six months.

6. Gifts to aged, blind or disabled individuals in the form of commercial transportation tickets would not be counted as income.

7. Property essential for self-support would not be counted as a resource. Only income from such property is to be counted in determining eligibility.

Elderly fall through Social Security's safety net

By John Robin Witt
Bee Staff Writer

– America's elderly. Their generation built Social Security from the gloom of the Depression, and primed it with their labor in the mines, the foundries and the auto factories. For most, Social Security was a New Deal hope for an uncertain future. But for others, the bright promise of retirement has dimmed.

Old age is not what a large number of them expected.

Why? Nearly 30 percent of those who are 65 or older and who rely solely on Social Security fall below the federal poverty level. That's 1.7 million people, according to the Social Security Administration.

And benefit increases slated to take effect next year still fall short of the need.

The stories of those on the Social Security margin are as varied as the individuals themselves.

In Rio Linda, 75-year-old former logger Marvin Rowe, too busy to worry about a pension when he was employed, stretches $18 worth of groceries over two weeks.

Noah Cloud, 80, who once supported himself well as a dry-cleaning repairman, runs out of money in the middle of the month. He's too proud to ask for more.

And disabled Korean War veteran Don Sower says poor retirees are not asking for a handout, merely for what they earned.

"I've paid my dues," he says.

The problem is not Social Security itself. The dilemma is this: Social Security was designed to serve as an essential safety net for retiring senior citizens but for too many, it simply is not enough, according to government reports and interviews with social workers and retirees.

The maximum Social Security benefit is $838 a month. For a home-owning couple, both drawing the maximum benefit, that may be enough. But the top payment for those on Supplemental Security Income, a kind of federal welfare for the old and disabled, is $575. On Jan. 1, Social Security will rise to $899, and SSI will increase to $402.

Of course, Social Security never was designed to serve as the sole support for the retired.

"The idea was to encourage people to save money, giving them a basic floor that they could add to," said Pamela Reim, deputy director of public affairs at Social Security's regional office in San Francisco.

But according to "Aging America," the official publica- n of the U.S. Senate Special Committee on Aging, "The elderly depend more heavily on Social Security for their income than they do on any other source." The U.S. Census Bureau notes that from 1968 to 1985, Social Security grew from 34.2 percent to 45 percent of income for people 65 years or older.

It is clear that for the retired poor, the increases are not keeping up.

"They raised their families and they worked and then they expected to die," says Charlene Silva, assistant director of Sacramento County's Adult and Aging Division. "Then they found themselves in a society that made sure they were going to live longer."

An estimated 120,000 elderly live in Sacramento County. Although no agency keeps track of the total number of elderly on Social Security in the county, officials agree that many live on Social Security and are poor.

"Sacramento County's current seniors ... are not financially well-prepared for their unexpected longevity," wrote Carole Wolff Barnes in a recent study.

Barnes, a professor of sociology at California State University, Sacramento, said that today's elderly often didn't expect to live as long as medical science has allowed. Moreover, the Depression sapped them, robbing them of educational and job opportunities that would have made the retirement years easier.

In their youth, they were the broad-shouldered work force of America: the blue-collar employees, the military veterans, independent people who raised families and asked for little but a paycheck — and rarely expected a pension.

But something happened along the way. They became old. And at the same time, many became poor.

"They are symbolic of the change away from the manufacturing economy to a service society," said the Camellia Center's Frank Buck, who has seen this trend in scores of low-income retirees at the drop-in center in downtown Sacramento.

Once the sinew of America's economy, many Social Security retirees sense that the dream somehow betrayed them.

"If it wasn't for places like the Camellia Center, I'd go hungry," said Sower, 58, who exists in a downtown apartment on just less than $600 a month from Social Security and SSI.

"I served in Korea. I've paid my dues and I paid into the system all my life. Now they act like I'm asking the moon. That just ain't right. Look at these people," he said with a sweeping gesture. "It's not that they won't try. It's that they have nothing to try with."

Still, the case of former logger Rowe is an example of how the elderly watch themselves being devalued in a youth-oriented society.

"When the work ran out, I'd go. But I wouldn't job hop," explained Rowe, coughing spasmodically — the wages of a cancerous lung. "I worked one place for six years. I was just too busy finding a job, keeping a job, to worry about retirement. I never thought about no damned pension."

An Army veteran, Rowe lives in a modest home in a low-rent area of Rio Linda. His income is $575 a month, a mixture of Social Security and SSI. Of that total, $250 goes to rent, about $50 for food and $200 for miscellaneous items — including a large portion for medication for lung cancer diagnosed after almost a half-century of smoking.

On a recent day, he climbed into his open-air AMF Harley-Davidson golf cart for a bone-chilling trip to the store underneath leaden skies that threatened rain.

The cart is his last link to mobility, and to a fierce independence he is unwilling to give up.

"It's the only thing I've got," he said, dismissing the tortoise-paced and bumpy ride to the market.

"I ain't gonna lay down for nobody. But sometimes, nobody opens the (heavy and locked garage) door for me, and I'm stuck here all day."

But not today. First there was a trip to the bank. Then to the service station to fill up his golf cart with a mixture of gasoline and oil. And finally to the market, where $17.13 bought the bulk of a week's worth of groceries: a large pack of cheese, a quart of milk, instant oat meal, two tins of smoked oysters and a 10-pound sack of potatoes.

Or there is Cliff Coin, 62, who retired three years ago after a life as a boilermaker and assorted work on the California Aqueduct. His combination of Social Security and SSI pay for a downtown apartment, food and medication for pain and high blood pressure.

"You walk into the store with 50 bucks and come out with couple of little bagfuls," Coin said. "Then you can't afford to take a cab home. When it's over, I don't have anything left. I have to rob Peter to pay Paul."

And there is Noah Cloud, 80, who says he makes the maximum in Social Security. Actually, he is secretive about his finances, considering it a private affair.

"I can barely make it," he said. "By about midmonth, I begin to run out of money. But I have so much pride I won't ask anybody for money."

Rowe, Coin, Cloud and Sower are the flesh on the frame of government statistics showing that a growing number of Americans are reaching old age in poverty.

However, some share the affluence of the general American population. Of those between 60 and 64 years old, 45 percent make $20,000 a year or more, according to Kay D. Merrill, a planning consultant with the Sacramento County Commission on Aging.

But those are the lucky ones — lucky enough to have earned a pension or forward-thinking enough to have saved or invested. Many did. Others did not.

"You probably could squeak by if you owned your own home, if you are not too disabled, if you don't have any health care costs and if you use the food and clothes closets. Not very well, but you could make ends meet, using all the community services," said Madalyn Craviotto, a supervisor with the county's Adult and Aging Division.

And does she know any who squeak by very well?

"Not very many," she said, reflecting. "Ten percent maybe. Really, practically none. It's a real struggle."

"Some people just had the misfortune of retiring before inflation took off, and never thought they'd see 90. They retired at 60 in 1968 with a very respectable pension of about $500. But as they went through the 70s, they went to the status of poor people.

"They lived too long. And this is their reward for it."

Jim Lightfoot

OPENING STATEMENT OF THE HONORABLE JIM LIGHTFOOT

SELECT COMMITTEE ON AGING
COMMITTEE ON WAYS AND MEANS. SUBCOMMITTEE ON HUMAN RESOURCES
SUPPLEMENTAL SECURITY INCOME ISSUES
MARCH 2, 1989

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE, DISTINGUISHED PANELIST AND GUESTS:

I AM PLEASED THAT BOTH THE SELECT COMMITTEE ON AGING AND THE WAYS AND MEANS SUBCOMMITTEE ON HUMAN RESOURCES SCHEDULED THIS HEARING TO RECEIVE TESTIMONY FROM OUR PANELISTS REGARDING THE SUPPLEMENTAL SECURITY INCOME PROGRAM (SSI). I LOOK FORWARD TO YOUR TESTIMONY AND WELCOME YOUR INPUT ON THE CURRENT SSI PROGRAM AND HOW SSI CAN BE STRENGTHENED FOR FUTURE ELDERLY AND DISABLED BENEFICIARIES.

THE SSI PROGRAM HAS PROVIDED AN EFFECTIVE SAFETY NET FOR QUALIFYING AGED, BLIND, AND DISABLED BENEFICIARIES. I WELCOME ADDITIONAL INPUT ON THE CURRENT BENEFIT LEVEL, PROBLEMS ASSOCIATED WITH DISABLED CHILDREN, AND FINALLY THE SOCIAL SECURITY ADMINISTRATION'S PROGRAMS TO REACH POTENTIAL SSI RECIPIENTS.

MR. CHAIRMAN, I REPRESENT A RURAL CONGRESSIONAL DISTRICT COMPRISED OF A LARGE NUMBER OF OLDER AMERICANS. I AM CONCERNED THAT SSI SHOULD BE AVAILABLE TO OUR NATION'S HARD-TO-REACH-POPULATION, PARTICULARLY IN RURAL AREAS. OLDER AMERICANS OR DISABLED INDIVIDUALS WHO RESIDE IN RURAL AREAS MIGHT NOT BE AWARE OF THE SSI PROGRAM, ITS BENEFIT LEVELS, OR THE ELIGIBILITY REQUIREMENTS.

IN ADDITION, I RECEIVE A NUMBER OF LETTERS FROM SENIOR CITIZENS WHO FIND IT DIFFICULT TO AFFORD HIGHER LIVING EXPENSES ON A FIXED INCOME. FOR A SSI RECIPIENT, COST-OF-LIVING INCREASES CAN BE ASTRONOMICAL. I UNDERSTAND THE BUREAU OF LABOR STATISTICS RECENTLY CONDUCTED A SURVEY WITH RESPECT TO CONSUMER PRICE INCREASES FOR OLDER AMERICANS. THOSE SURVEYED SPENT APPROXIMATELY 10 PERCENT OF THEIR INCOME FOR MEDICAL FEES. FORTY-NINE PERCENT OF THEIR INCOME WAS NEEDED TO PAY FOR HOUSING. LESS MONEY WAS SPENT ON FOOD, CLOTHING, TRANSPORTATION AND ENTERTAINMENT. THE BUREAU FURTHER FOUND THAT BETWEEN 1982 AND 1987, CONSUMER PRICES ROSE 19.5 PERCENT FOR THE ELDERLY. THEREFORE, I LOOK FORWARD TO RECEIVING TESTIMONY EXAMINING THE CURRENT BENEFIT LEVEL.

MR. CHAIRMAN, THANK YOU AGAIN FOR SCHEDULING THIS HEARING SO THAT BOTH SELECT COMMITTEE ON AGING AND THE SUBCOMMITTEE ON HUMAN RESOURCES HAS AN OPPORTUNITY TO RECEIVE INPUT.

Chairman **Roybal**. The Chair is now privileged to introduce a young lady that came all the way from Indianapolis to be with us and to testify before this committee. She is here on behalf of the Villers Advocacy Associates from Indianapolis and is accompanied by Nancie Stutzman, who, incidentally, is her social worker.

We are particularly interested in hearing from Ms. Bey. Not because she is young at age 97, but because she has a lot of experience, a lot of background that she wants to relate to this committee.

She will describe her experience living on an income which totals about $13 per day. Now as you know, this is the current maximum Federal benefit under the SSI program, which is supposed to be designed to provide a safety net for the elderly, the blind, and the disabled.

Ms. Bey, the Chair now recognizes you and asks you to proceed in any manner that you may desire.

STATEMENT OF BLANCHE BROWN-BEY, SSI RECIPIENT, ON BEHALF OF VILLERS ADVOCACY ASSOCIATES, INDIANAPOLIS, IND., ACCOMPANIED BY NANCIE STUTZMAN, SOCIAL WORKER

Ms. **Brown-Bey**. Good afternoon. I am Mrs. Blanche Brown-Bey. I live at 2353 North Rural. My telephone number, 638-6923. My birthday is August 17, 1891.

Now I will start on my income. My income is $356.20. My Social Security is $253, and my supplemental security income is $103. I bought my house in 1921 and I paid for it in 1950. I moved to New York from Indianapolis in 1930. I worked at a company named Cohen & Cohen Co. I made toys and button-hole stitched in a laundry.

I was married to Mr. Wady and I separated from him in 1930. Then I went to New York. My sister was ill, and I went to New York and married Alexander Brown-Bey, which I have my name now. I was divorced from him in 1940.

I moved back to Indianapolis and my home, 2353 North Rural. My house payment was $40. I finished paying for my home then. Even so, each year now in May and November I pay my taxes on my home. The amount is $74.

My utilities are very high. They have gone up. My gas bill runs very high, which is $140. My electric is $35 per month. My sewer is $6 and my water is $3.50. My phone bill is $19.21 each month. Now how I get my bills paid each month, I do not get enough money. They are always in arrears. I have to wait till I get this check to pay and then I have to pay a late fee.

I signed up for Project Safe in January. They pay just a part of it. They pay $210 for my gas and pays $50 for my electric. My life insurance is 35 cents per week. That makes $1.51 a month, I think it is, they collect from me. My house insurance is $286. I pay that in November.

Now my food situation, the food stamps were giving me $10 per month. And they wanted me to send them my mother's maiden name and my bills which were strewn around. I did not send them and they stopped giving me anything. The food stamps do not give me anything. My neighbors have to come in and bring me food, so long as the food stamps do not give me anything. I have two neighbors that go and get my groceries. They buy for me chicken and eggs and milk and such; that is, perishables, food stamps do not give me. Some neighbors give me a bag of food once a month.

I am telling you my experience. I have it written down here but I cannot remember everything. I will just have to tell you. I jotted it down here.

I have to pay for someone to go and get my food. I am not able to go get it.

My doctor's bills—I do not have to pay my doctor. I go to Wishes Hospital. The CCI takes me free; a company takes me free. I do not have to pay anything for my prescriptions now. I do have to pay—my doctor has me on a tonic. They call it Sustacal. They used to call it Ensure. I have to pay for that, and that is $1.29. The doctor does not prescribe that every time and I have to go and get it some other way. It is $1.29 per can and I have to drink three cans a day, after each meal.

I have a nurse that visits me twice a week. My homemaker comes sometimes. That is the truth about it. My nurse, she gives me my bath and takes care of my personal needs. My homemaker cleans up my house, when she comes. I get that free through title XX.

I have a Lifeline furnished to me. I do not have to pay for that. They ask me for a donation and I do not ever have that. That is my experience. I am telling you the truth. Nobody knows about it but me.

There is a woman calls me every morning around 10:00 from the community hospital. That is the Telecare. During the summer, my caseworker brought me a fan. I get a Thanksgiving and Christmas basket from my church.

I have my plot paid for in Crown Hill. That is all.

You can ask me any questions. Any more questions you want to ask? Maybe I have forgotten some of them. I was just 97 years old and I cannot think of everything at all times. I will be 98 in August.

[The statement of Ms. Brown-Bey follows:]

Blanche E. Brown-Bey
2353 N. Rural
Indianapolis, Indiana

Date of Birth: 8/17/1891

Income: Social Security - 284.90
Supplemental Security Income - 103.10
Eligible 1/1974

Mr. and Mrs. Waddy (Blanch-Bey) bought the home that Blanche currently lives in around the year 1921. Mrs. Brown-Bey worked for eight years in New York in a toy factory between the years of 1930 and 1940. The Wady's separated and divorced in 1940. She payed the remainder of the house payments at $40.00 per month. The house was paid off in 1950. She had moved back to Indpls. in 1940 to stay. Currently she pays her home owner taxes in two payments. They are $34.00 each time and are paid in November and May. In order to make this additional payment, Blanche will do without something else that she may need.

Blanche pays all of her utility bills after she receives her checks. Her bills are usually due before these checks arrive and Blanche ends up having to pay an additional fee for late charges. Of course these utilities vary. The approximate amount each month is broken down like this:

Electric: $35.00 She usually keeps the lights off except for one small 40watt bulb she burns at night.

Gas: $140.00 This is for the winter months.

Phone: $21.00 Basic service with no long distance or added features.

Sewer: $6.00

Water: $3.50

With regard to food, Mrs. Brown-Bey buys what perishable items she can afford. This usually includes bread, eggs, milk, margarine, some fruits like bananas, oranges, and apples, and her meat is generally chicken as it is less expensive than beef. A friend will usually do her shopping for her and she pays him $10.00 for his time and effort. She is eligible for $10.00 worth of food stamps. These were cut off a few months ago after some confusion about recertification. Mrs. Brown-Bey will be applying again next week. She was under the impression that if she had food stamps, her monthly bag of canned goods would cease. These groceries come from a church in our city that aids seniors who generally run short of food toward the end of the month. She also receives a Thanksgiving and Christmas Basket each year as well. Her neighbors and church members will sometimes bring her a plate of food already prepared. Her doctor has told her to drink one can of Sustacal in between each meal. This supplement comes from the county hospital. However, as Mrs. Brown-Bey is in fairly good health, she doesn't go to the hospital very often. She usually runs out of this and if she is able to buy any more, it costs her approximately $1.29 per can.

Mrs. Brown-Bey receives several community services here in Marion County. Project Safe awarded her $210.00 toward her gas bill for heat this winter and $50.00 toward the electric. This is a program that is implemented each winter.

She receives a homemaker one morning every two weeks and a home health aid to assist in personal care two times per week. This enables Mrs. Brown-Bey to live as independently as possible. These services are provided through Visiting Nurse Service and is funded by Title XX. She realizes how fortunate she is to receive this as she was on an extremely long waiting list and could not pay for it privately.

Telecare is a service of volunteers at a local hospital. These people call the client one time per day to make sure they are okay.

Another hospital provides a system called Lifeline. This is an emergency button wired through the telephone that a person can push and call for help. They ask for an $8.00 per month donation, however, Blanche does receive hers at no cost.

Last summer a fan was provided through the Community Action Against Poverty and some local, private donations.

Mrs. Brown-Bey has been asked if she would like to apply for Medicaid. However, she is concerned that her house will have to be signed over. She wants to leave this to her grandaughter to cover funeral expenses. This is also what her small amount of money in the bank is set aside for. Her health care is provided by the county hospital. She is on Complete Indigent status and is not charged for her care or prescriptions. This hospital is supported by county funds but loses money continuously. The care is good for the number of people they serve however, the wait to get in is quite lengthy. Mrs. Brown-Bey is in wonderful health for her 97 years. She does have high blood pressure as well an incontincy problem that is common to most seniors. Mrs. Brown-Bey is unable to afford incontinent supplies and does without. This is difficult for her. She relies on friends and neighbors to get her to her various appointments

As I said earlier, Mrs. Brown-Bey realizes how fortunate she is to receive these many services as many seniors do without. She is appreciative of the help she receives.

Chairman **Roybal**. Ms. Brown-Bey, what I am going to try to do is to ask the members of the committee, first of all, if they have any questions to ask. Then if they do not, we would like to summarize your testimony and then go on with the other witnesses.

The Chair now yields to Congressman Downey.

Acting Chairman **Downey**. Ms. Brown-Bey, is the amount that you get from the Government enough?

Ms. **Brown-Bey**. I did not understand you.

Acting Chairman **Downey**. Is it enough money?

Ms. **Brown-Bey**. No, I do not get enough. My bills are always running in arrears. I have to wait for one check to pay, and the next check—I have to wait for the next check. That keeps me in arrears all the time.

Acting Chairman **Downey**. So if we gave you a little bit more it would help you with the bills that you run behind with.

Ms. **Brown-Bey**. Yes, that is what I am here for. I want more money. [Applause.]

Acting Chairman **Downey**. You are too tough a witness for me. I have no further questions, Mr. Chairman.

Chairman **Roybal**. The Chair now recognizes Mr. Shaw.

Mr. **Shaw**. Thank you, Mr. Chairman. I believe after Chairman Downey's question that I will forgo the right to further question this witness. I must comment though in passing that she is certainly a remarkable woman with a remarkable mind. Thank you.

Chairman **Roybal**. Thank you.

Mr. Hertel.

Mr. **Hertel**. Ms. Brown-Bey, I can understand how very difficult it is today on what averages out to be $13 per day. But is it even worse than it was say 5 years ago. We hear so much about lower inflation over the last 4 years until the last few months. But is it even harder than it was for you 5 years ago on what you receive?

Ms. **Brown-Bey**. Why sure it is. Everything has gone up, bills and everything. Utilities bills are almost twice as much. Everything is just so high it almost takes my breath when I hear it.

Mr. **Hertel**. Thank you, Ms. Brown-Bey.

Chairman **Roybal**. Mrs. Bentley.

Mrs. **Bentley**. No questions, Mr. Chairman, other than to say she is a remarkable lady and her testimony is certainly something that we need to look at.

Chairman **Roybal**. Thank you, Mrs. Bentley.

The Chair recognizes Mr. Volkmer.

Mr. **Volkmer**. Mr. Chairman, if it is permissible, I would like to ask Ms. Stutzman a question rather than Ms. Brown-Bey in regard to services that are available in Indianapolis for our senior citizens.

Back in Missouri where I am from, in my district we have the Meals-on-Wheels program. Do you have that in Indianapolis?

Ms. **Stutzman**. We have both home-delivered meals and Meals-on-Wheels for people who are diabetic. Meals-on-Wheels costs $18 a month, I believe. Ms. Brown-Bey has been offered home-delivered meals. However, she believes that her own cooking is better for her; that that is how she has lived to be 97 years old. She is a little bit hesitant about trying those out.

Mr. **Volkmer**. In other words, that has been made available to her if she wishes it.

Ms. **Stutzman**. She has been offered. I think she tried it for a while and decided that other people could probably benefit more from it as she is still able to do some of her own cooking also.

Mr. **Volkmer**. Thank you very much.

Thank you, Mr. Chairman.

Chairman **Roybal**. Ms. Schneider.

Ms. **Schneider**. No questions.

Chairman **Roybal**. The Chair now recognizes Mr. Costello.

Mr. **Costello**. I have no questions, Mr. Chairman.

Chairman **Roybal**. Thank you.

Mr. Kennedy.

Mr. **Kennedy**. Ms. Brown-Bey, I have two questions. I wonder whether or not you have any friends that find themselves in the same circumstances that you do? Do you have friends or neighbors that also are having trouble because they are on SSI, supplemental security income?

Ms. **Brown-Bey**. Yes, I have plenty, thousands of them telling me how the situation is with them such as it is with me. That is why I am here.

Mr. **Kennedy**. Yes, ma'am. You find that your friends are in the same circumstance of having to make very tough choices in terms of how they are going to spend the few dollars they get from the Government?

Ms. **Brown-Bey**. Sure, my friends are in the same position that I am in. They too make choices, sacrifice and do without like I do.

Mr. **Kennedy**. I think it is terrific that you have come down to this hearing today, ma'am. I think that the people that are up here on this panel are very interested in trying to make the payments more equitable to our nation's senior citizens that have done so much for our country. So I hope we will take action on your needs as well. Thank you very much for coming down.

Chairman **Roybal**. Thank you, Mr. Kennedy.

The Chair recognizes Mr. Matsui.

Mr. **Matsui**. I have no questions, Mr. Chairman. I would just like to tell Mrs. Brown-Bey that she is just a very remarkable lady and I want to thank her for her testimony.

Chairman **Roybal**. Thank you.

Mrs. Kennelly.

Mrs. **Kennelly**. Thank you, Mr. Chairman, no questions.

Thank you, Mrs. Brown-Bey.

Chairman **Roybal**. Thank you.

Ms. Brown-Bey, we greatly appreciate your testimony. As you were testifying I took down some of the figures that you were referring yourself to. We find that your income is approximately $380 a month. That your expenses, just for electricity, for gas, phone, sewer and water is $205 a month. That leaves a remainder of $175 a month which must provide for food, for taxes, for clothing and everything else.

Now if you divide that by 30 then the dollar amount on a daily basis is even worse than originally testified to, because these things, these utilities and so forth, they have to be paid. The taxes have to be paid and that was not included in the testimony that you have given.

So we find that you are just one of 4½ million Americans that at the present time are receiving SSI assistance. It is estimated that of those 4½ million that there is at least between 1.5 and 1.75 million Americans that are over the age of 75. Now this is a tremendous number of individuals who are existing in this Nation with an income of around $13 per day. Then when they pay all utilities and everything else, then we find it is even much less.

The one question that I had in mind was something with regard to the assistance that can be given by the county. It is my understanding that if such assistance is sought that the property of the individual would have to be given or a lien would have to be placed on that property. Ms. Stutzman, is that the case also in your State?

Ms. **Stutzman**. In Marion County we have title XX services and we also have different county services that are not covered by title XX. It is my understanding that with Medicaid you have to sign over your house to get medical assistance. For any type of area program, there is only one that I could think of that sometimes does that. It is a housing improvement type of program where they will come in—if Ms. Brown-Bey's ceiling fell through and it started leaking or something and she could not afford to pay for it, if she was not able to get the money together herself through family or friends, we could possibly go to this agency if they had any moneys available. But they would probably want something in return.

Chairman **Roybal**. Now if an application is made for Medicaid, she will then have to sign over her house; is that correct, in order to comply?

Ms. **Stutzman**. I do not know that they always will come back and take that against their estate once a person has died, but it is my understanding.

Chairman **Roybal**. I am thinking primarily of the so-called reverse financing where the individual places the home and then money is drawn against the value of that home. At any rate, what does happen is that that individual then just turns over the home to Medicaid in this instance and eventually loses that home; is that not correct?

Ms. **Stutzman**. That is my understanding.

Chairman **Roybal**. I know that that is the case in Los Angeles County and I just wanted to know if that was something that one has to contend with no matter where we go in this nation.

Are there any other questions for Ms. Brown-Bey from members of the committee?

[No response.]

Chairman **Roybal**. If not, Ms. Brown-Bey, we would like to thank you for your testimony. We greatly appreciate the fact that you came all the way from Indianapolis to talk with us. Let us see what we can do. We will look into this situation and find out if the Congress some way can make things better. We do not know that we can, but I can assure that this committee is looking into the possibility that something better can be done, and I hope this year or the next. I thank you very much, Ms. Brown-Bey, for your testimony.

Ms. **Brown-Bey**. Thanks for the opportunity to come as a witness and giving you my experience. To start with, they are not getting enough SSI. Are you going to increase it? That is what I am trying to ask. That is what I want to ask you.

Chairman **Roybal**. Ms. Brown-Bey, if it was up to me, I would have increased it a long time ago, but it is not.

Ms. **Brown-Bey**. Others than myself are not getting enough SSI money to cover their expenses. They want to know, and I am asking you, are you going to increase it?

Chairman **Roybal**. Ms. Brown-Bey, that is a $64,000 question that is constantly asked of Members of Congress. The purpose of these hearings is to, first of all, make a final determination as to what the conditions are, what the facts are. We will make recommendations to the appropriate committee. Mr. Downey sits on the Committee on Ways and Means.

We hope that as we go along we can improve the situation. This is a very friendly committee, one that is constantly trying to work out things. We hope that we can do it, and we hope that we can do it quick enough to fast enough for you to benefit from that action.

Ms. **Brown-Bey**. Thank you.

Chairman **Roybal**. Thank you very much.

The Chair now would recognize as a panel the following individuals. First of all is Dr. Elizabeth Boggs, the parent of a mentally disabled child. She will discuss her experience concerning how well SSI meets the needs of disabled individuals and their families; Mr. Michael Carozza; Mr. William Shelton, who is a social worker; and also Mr. Pollack. The Chair will recognize Dr. Boggs first.

STATEMENT OF ELIZABETH M. BOGGS, PH.D., MEMBER, GOVERNMENTAL AFFAIRS COMMITTEE, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES, AND PAST PRESIDENT OF ASSOCIATION FOR RETARDED CITIZENS, HAMPTON, N.J.

Ms. **Boggs**. Thank you, Mr. Chairman. I am representing the Association for Retarded Citizens of the United States of which I was a founder in 1950. And as you have just mentioned, I have a son who is now 43 years old who is profoundly mentally retarded and also has several other handicaps, including uncontrolled seizures. He receives adult disabled child's benefits under the Social Security program on the record of his deceased father. He is not himself recipient of SSI, but many of his contemporaries are.

I mentioned him in particular, not merely as a qualification, but because he was born 2 weeks after the end of World War II, and in a certain sense he represents a watershed in the populations that we need to talk about here. He belonged to the last of the low birth rate cohorts of 1931-45. But he also partook of the future because the fact that he was born 2 weeks after World War II meant that his life was safe because penicillin became available in civilian hospitals, after it was no longer needed exclusively by the military. And as a result of that he lived whereas he otherwise would have died.

We know that many youngsters, infants and young children with disabilities died during the Depression, and we know that in the expanded birth cohorts, the high birth rate cohorts of the 1960's, we had many survivors, and those people are now young adults. I want to speak particularly about the adult SSI populations, since there are other speakers who will speak to the children's issues.

You have as the last page of the written testimony submitted by our organization, which I assume will be inserted in the record, a table showing some of the shifts in populations which Congressman Downey referred to in his opening statement. And I would like to refer to those also. The shifts have interesting explanations. For example, it has been fairly clear over the past 10 or 12 years that the number of elderly people who have been receiving SSI has been gradually declining, both in numbers and in relation to the population of which they are apart. This is a good sign. It means that the overall intent of SSI and Social Security is succeeding to some extent because fewer elderly people need SSI inasmuch as Social Security itself is becoming more adequate for more people.

You will notice at the other end of the scale, however, that the proportion of young people is increasing. The overall total number of people receiving SSI has increased very slightly between 1977 and 1988, but the percentages by specific age have shifted enormously and, with them, the numbers in specific age categories. Actually the particular figures in table 1 may be a little bit hard to interpret at the outset because the age groups are not quite all the same size. But if you were to get equal or use equal 10 year age cohorts for a table like this, you would find that the largest single cohort is those from 20 to 29.

These people by and large have been disabled since childhood. One of the reasons they need SSI is that they have never been in the work force and they have never accumulated the perquisites that go with being in the work force, the fringe benefits and so forth.

Of those between 20 and 25, almost half are mentally retarded, and if you consider other mental disabilities, it is 70 percent, and that goes also for the 25 to 29 cohort. These people have grown up in a generation which has had more access to schooling than more disabled children had 20 or 30 years ago, and they and their parents have aspirations for them to participate as nearly as possible in the mainstream of life, more particularly to be productive and to engage in some sort of work. This committee has been instrumental in assisting with the enactment of Section 1619 (a) and (b) of the Social Security Act which has made it possible for these young adults to attempt work when they otherwise might have been afraid of losing benefits which they very much needed.

Nevertheless, they are marginal workers. They are in and out of the work force. They do not have jobs which bring good fringe benefits, good benefit packages, good health care packages, and so forth. So they are very vulnerable. And one of the vulnerabilities they are exposed to arises if there is anything that reduces the maximum SSI payment level at which they are eligible; they are more likely to lose their Medicaid than if those reductions did not take place. Therefore. so I want to commend and support those provisions in the bills which deal in two ways with people who have reductions in net benefits—but not net income—one, reductions because they are frugal enough to maintain what assets they have in a savings account, instead of spending them, and hence have "countable" interest and two, the reductions that may occur where workmen's compensation is counted.

So on behalf of that particularly large young group who need stability in their support, and need the knowledge that somehow they can try out in the work environment, I particularly commend the adjustments that you are proposing to make to supplemental security income standards.

I do, of course, feel that a fraction of the poverty level is clearly not consistent with an opportunity for people to live in dignity and individuality, but I think you have had adequate testimony on that subject.

I repeat that we stand in support of all of the bills that are before you and commend the people who have been very careful to work out the technicalities. And I thank you.

[The statement of Ms. Boggs follows:]

TESTIMONY OF ELIZABETH M. BOGGS, PH.D.
ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

On behalf of the Association for Retarded Citizens of the United States (ARC), I want to thank the Ways and Means Committee's Subcommittee on Human Resources and the Select Committee on Aging for this opportunity to testify regarding the Supplemental Security Income (SSI) program and changes needed in the program to help improve the lives of persons with disabilities.

The ARC is the largest voluntary organization in the United States devoted to securing the rights of, and effective services for, the approximately six million citizens with mental retardation in this nation. Its national membership numbers over 160,000 people, more than half of whom are parents of children and adults with mental retardation and includes people who are mentally retarded themselves. The ARC has approximately 1,300 state and local chapters throughout the country. Since its founding in 1950, the ARC has participated actively in the formulation of public policy with respect to the rights of, and services for, citizens with mental retardation, including public policy concerning the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs.

As of June, 1988, people with mental retardation made up almost 25 percent of the adults of working age (18-64) with disabilities on SSI. There is reason to believe that another 10-15 percent of SSI recipients have been disabled since childhood. People with mental retardation, along with persons with other mental disorders, constituted over 64 percent of the persons who were using the Section 1619(a) work incentive provisions and over 53 percent of the persons who were using the Section 1619(b) provisions. The response to the Section 1619 amendments since 1987 has been most gratifying to us and to SSA and is a credit to its supporters in the House.

These SSI beneficiaries are dependent upon SSI and Medicaid for many of their basic needs such as food, shelter, clothing, and medical care. Because of the importance of SSI and Medicaid benefits, it is necessary for Congress to continually reexamine the program and to make improvements and changes necessary to fulfill the intent of the program and to remove unintended and unnecessary obstacles which face many current or potential beneficiaries.

SSI beneficiaries are not a homogeneous group. Moreover, there have been a number of demographic changes in the SSI population since 1974. Although the total number of recipients has increased by less than three percent, the number of recipients under 40 has doubled, as indicated in Table 1. Our oral testimony will focus on this younger group.

The ARC is pleased to see the introduction of five bills which, if enacted, would go a long way toward making necessary improvements in the SSI program:

- H.R. 360 - "SSI Asset Reform Act of 1989"
- H.R. 361 - "SSI Benefit Level Reform Act of 1989"
- H.R. 866 - "SSI Benefit Improvement Amendments of 1989"
- H.R. 867 - "SSI Technical Amendments of 1989"
- H.R. 868 - "SSI Disabled Children Act of 1989"

Because these bills are designed to resolve a number of problem areas which have been identified in the SSI program, our testimony will highlight some of the most important provisions of the bills. The ARC urges the Subcommittee on Human Resources to carefully consider the merits and importance of the bills and to act expeditiously in moving these bills toward House passage this year.

1. Increase in the SSI benefit level (H.R. 361 and Section 101, H.R. 866)

An increase in the federal SSI benefit standard is desperately needed. Poor individuals and families who are solely dependent on SSI are living far below the poverty line. Steps should be taken immediately to increase the benefit level gradually over time to bring the amount up to the poverty line. The SSI program goal of guaranteeing a minimum level of cash to persons who are elderly or disabled has not yet reached the point of assuring that those persons can live even at poverty standards. It should be remembered that the poverty level only measures the cost of a low cost nutritional diet plus two times that amount for coverage of other basic necessities.

2. Increase in SSI resource limits (H.R. 360 and Section 201, H.R. 866)

The SSI resource limits are also drastically low ($2,000 for an individual and $3,000 for a couple). The resource limits do not enable SSI recipients, particularly those who work using the Section 1619 work incentive provisions, to save money to reasonably meet unexpected expenses or emergencies. A more realistic level should be set for the resource limits. H.R. 360 and H.R. 866 propose an increase to $4,200 for an individual and $6,300 for a couple which will restore the resource level to the approximate value of the resource limits in 1974, when the limits were first established.

3. Change in the treatment of in-kind income for persons living in the household of another (Section 102, H.R. 866)

Changes are needed regarding the calculation of the reduction of the federal SSI benefit level to account for in-kind support received by a beneficiary while living in the household of another. The calculation should be changed to call for a reduction equal to the lesser of the value of the current one-third reduction or the actual value of the assistance received. This provision would primarily benefit very low income persons where the value of the in-kind assistance received is less than one-third of the federal benefit standard. This would affect persons in homes where household expenses are lowest and would remove a sort of Catch-22 which now hurts the very poorest of SSI beneficiaries.

4. SSI status to be deemed for certain persons with in-kind income (Section 103, H.R. 866)

Currently, there are many persons who have some non-SSI income (which may be income from Social Security Disability Insurance (SSDI)) and who also receive in-kind assistance. Many are not SSI eligible because, due to their receipt of in-kind income, in determining SSI eligibility, their other income is applied to the reduced SSI federal benefit level (two-thirds of full benefit level). This typically may happen to an adult disabled during childhood (DAC) who receives a relatively modest dependent's or survivor's benefit as a result of an insured parent's disability, retirement, or death. If the person lives at home with a parent or relatives, application of the Social Security and other income against two-thirds of the federal SSI benefit standard may leave the individual ineligible for SSI, and therefore Medicaid, even though his cash income is less than the SSI standard. Section 103 of H.R. 866 would deem that person to be SSI eligible for purposes of Medicaid. For many persons with developmental disabilities, Medicaid eligibility is necessary in order to have certain non-institutional long term care needs met through Medicaid reimburseable programs.

5. Establishment of a permanent SSI outreach program (Section 301, H.R. 866)

To ensure that the maximum number of eligible persons are aware of and apply for their benefits under the SSI program, the Social Security Administration (SSA) should be required to engage in an ongoing outreach program. SSA is in a unique position to do two things:

1) identify those persons who apply for Title II retirement and disability benefits and their dependents who are likely to be eligible also for SSI; and

2) provide general and technical assistance to those federal, state, and private agencies and non-profit organizations who come in contact with other persons who are also likely to be eligible for SSI.

Special outreach efforts should be required for children who are disabled or blind since the avenues for identifying them will be different than those for adults. In addition, the Secretary of Health and Human Services should be required to evaluate the effectiveness of the outreach programs and to make an annual report to Congress. It should be made clear that SSA may fulfill some of its obligations under this section through contracting with qualified parties.

6. Treatment of workers' compensation and unemployment compensation as earned income for SSI purposes (Section 101, H.R. 867)

Workers' compensation and unemployment compensation benefits should be treated as earned income for purposes of SSI. This proposed change could make a substantial difference to families struggling to meet expenses since earned income is treated more favorably than unearned income for purposes of SSI. Since workers' compensation and unemployment compensation are paid to a worker as temporary compensation for or replacement of lost earnings, treating these payments as earned income would more realistically carry out the SSI purpose of supplementing an individual or family's earned income. Time and other constraints now placed on these awards should suffice to offset any deterrent to reentry to the workforce.

7. Changes in eligibility determinations for weekly or biweekly income in certain months (Section 102, H.R. 867)

Changes are needed to resolve problems which beneficiaries encounter when they receive three biweekly or five weekly checks in a given month because of the way in which the weeks fall on the calendar. Curently, a person's SSI benefit is reduced or terminated when he/she or certain other family members receive an extra payment for the month. Section 102 would require the Secretary to consider the person's annual income and use an average monthly amount in calculating the SSI benefit.

8. Disregard of certain interest and dividend income (Section 105, H.R. 867)

This section would require the Secretary to disregard certain interest or dividend income equivalent to what the recipient might be expected to receive if he/she placed his/her disregarded assets in a savings account. This should encourage thrift at a time when capital formation is a desired fiscal policy objective.

9. Retention of Medicaid for additional adults disabled during childhood (Section 302, H.R. 867)

Currently, people who first become entitled to Title II disability benefits as adults disabled during childhood (entitled to benefits upon their parent's disability, retirement, or death) after July 1, 1987 are deemed to be SSI eligible for purposes of Medicaid eligibility. Section 103 would extend the date back to January 1, 1981 to cover more such persons who have lost eligibility to Medicaid due to Title II benefits. For these individuals, entitlement to Medicaid may be critical in paying for Medicaid-funded long term care services targeted specifically to persons with developmental disabilities.

10. Amendments to ensure appropriate transition to Medicaid for those deemed eligible (Section 303, H.R. 867)

Amendments are needed to address the problems encountered by people who lose eligibility for SSI cash benefits but who are deemed to be eligible for Medicaid benefits (such as certain adults disabled during childhood who receive Title II benefits as described in Section 302. A smooth transition into continued Medicaid eligibility is a goal that has not yet been achieved. Currently, there may be a gap in coverage until they go to the state Medicaid office to apply for benefits or if they fail to apply. Section 303 would provide that such individuals would be presumed to have filed for Medicaid and that their benefits would continue unless they are determined to be ineligible. Section 303 would also establish timelines within which certain determinations must be made in order to be effective retroactively.

Section 303 also provides that these changes in Medicaid eligibility determinations are to apply in "Section 209(b)" states.

11. Changes to the definition of disability for children (Section 2, H.R. 868)

Comprehensive changes are needed in the statutory definition of disability for children in order to ensure that children with severe disabilities, who should be eligibile for SSI, are properly identified and given benefits as early as possible. Congress is well aware of the benefits of providing needed services to children as early as possible to prevent the cummulative and costly effects of delay in providing those services. Section 2 would do several important things:

1) It would ensure that the Secretary will consider a child's functional limitations in determining whether a child meets the disability listings. This is not happening under current law and many children who are severely disabled are denied benefits because they do not meet the exact specifications of the impairment listings, regardless of their functional limitations.

2) It would create a presumptive eligibility for children who have congenital or genetic impairments if it is probable that, when

more accurate testing is available, the child will be considered to be disabled.

3) It would require the immediate publication of proposed rulemaking for revision of the childhood mental disability listings. A draft listing prepared by the SSA Mental Impairments Listing Workgroup has gone unpublished for nearly three years. The changes are long overdue.

4) It would require the Secretary to consult experts in childhood disability to consider changes which should be made to the full listing of childhood impairments and to publish proposed revisions to the listings.

12. Amendments related to resources (Section 3, H.R. 868)

Two amendments are needed relating to counting of resources for SSI eligibility. Included in Section 3, the two amendments would significantly affect children with disabilities in poor families who are now found ineligible for SSI benefits because of the current very restrictive rules. The first would ensure that resource exclusions are counted for each family member, particularly siblings of the child who is disabled, whose needs must also be met. The second would eliminate the current rule that may require the family to liquidate resources essential to its self-support in order to obtain Medicaid for the child. It tends to have especially harsh effects on poorer farm families with a child who is disabled. The amendment would require that the value of income-producing property would not be counted as a resource; rather the income produced by the property would be considered as income in determining whether a child is eligible for SSI.

Section 4 is necessary to ensure that SSI eligible children are considered Medicaid eligible in all states. It will help to make eligibility for vital services a bit more uniform for children across the country.

The ARC wholeheartedly supports the five bills discussed above and urges the Committee on Ways and Means to act expeditiously to pass them. We would also like to enter into the record a partial list of those national organizations which support enactment of H.R. 366, H.R. 367, and H.R. 368. As of February 24, 1989, they are:

American Academy of Child and Adolescent Psychiatry
American Association for Children's Residential Centers
American Association for Marriage and Family Therapy
American Association for Partial Hospitalization
American Association on Mental Retardation
American Occupational Therapy Association
American Diabetes Association
American Foundation for the Blind
American Psychiatric Association
Association for Retarded Citizens
Autism Society of America
Children's Defense Fund (H.R. 868 only)
Epilepsy Foundation of America
Family Services of America (H.R. 868 only)
International Association of Psychosocial Rehabilitation Services
Mental Health Law Project
National Alliance for the Mentally Ill
National Association for Rights Protection and Advocacy
National Association of Developmental Disabilities

Councils
National Association of Music Therapy
National Association of Private Residential Resources
National Association of Protection and Advocacy Systems
National Association of Social Workers
National Association of State Mental Health Program Directors
National Association of State Mental Retardation Program Directors
National Council of Community Mental Health Centers
National Federation of Societies for Clinical Social Work
National Mental Health Association
United Cerebral Palsy Associations, Inc.
World Institute on Disability

Again, I thank the Committee Chairmen and Members for your attention to these very important issues. We look forward to working with you further to ensure passage during this Congress.

TABLE 1

SSI: NUMBER AND PERCENTAGE DISTRIBUTION OF PERSONS RECEIVING SSI PAYMENTS, BY REASON FOR ELIGIBILITY AND AGE: DECEMBER 1975 AND SEPTEMBER 1988

Category of Age and Basis for Eligibility	December 1975		September 1988	
	Number	Percent of SSI Federally Admin. Payments	Number	Percent of SSI Federally Admin. Payments
Total	4,314,275		4,432,810	
A. Receiving SSI on Basis of Age 80 Years of Age and Older	692,132	16%	583,561	13.2%
B. Receiving SSI on Basis of Age Ages 65 - 79	1,614,973	37.4%	849,233	19.2%
C. Receiving SSI on Basis of Disability or Blindness Age 65 and Older	200,751	4.7%	570,113	12.9%
D. Receiving SSI on Basis of Disability or Blindness Ages 50 - 64	910,523	21.1%	827,186	18.7%
E. Receiving SSI on Basis of Disability or Blindness Ages 40 - 49	281,624	6.5%	377,999	8.5%
F. Receiving SSI on Basis of Disability or Blindness Ages 22 - 39	411,289	9.5%	831,084	18.7%
G. Receiving SSI on Basis of Disability or Blindness Ages Birth - 21	201,175	4.7%	393,254	8.9%

Chairman ROYBAL. Thank you, Dr. Boggs. The Chair recognizes Mr. Shelton.

STATEMENT OF WILLIAM S. SHELTON, SOCIAL WORKER, ON BEHALF OF DEVELOPMENTAL AND GENETIC CENTER, UNIVERSITY OF TENNESSEE, KNOXVILLE, TENN., ACCOMPANIED BY DONNA LEFEBVRE, ATTORNEY, LEGAL SERVICES OF TENNESSEE

Mr. SHELTON. My name is Bill Shelton. I am with the Developmental and Genetic Center at UT Hospital in Knoxville, Tenn. I am a master's level social worker there. I coordinate our home base preschool program and a diagnostics and evaluation program also.

Both the staff and myself have personally reviewed the legislation and I appreciate the opportunity to relate some professional opinions and some of our actual experiences. What I would like to do is talk with you in regards to three areas of this legislation. The first is the presumption area. We at the hospital work with a very large number of children who are diagnosed at birth or early infancy with disorders in which one of the key features is a very high probability that mental retardation will be present.

There are a very large number of these disorders, but what I would like to do today is use an example of a child with a diagnosis of Down's syndrome as a way to illustrate the difficulties these children have in dealing with SSI. When a child is diagnosed with Down's syndrome and it is confirmed through a chromosome analysis and it is virtually a given that there is going to be some degree of retardation present. Therefore we sit down with the parents at the time of diagnosis and advise them to apply for SSI. At the same time we tell them to be prepared to be denied and talk with them about the appeal process and tell them they may even have to go through and request an appeal hearing.

The reason we do this is it has been our experience that the majority of applications of children with Down's syndrome diagnosis are denied on the initial application. And we have on a number of occasions even had to go to an appeal hearing. And the reason for the denial is simply this. That when the diagnosis is made, it is made usually at birth or early infancy, and because of the age of the child, there is no way to get a specific IQ scoring. Therefore, when the application is made and all the material is in hand, even though the reviewer has a medical diagnosis that guarantees retardation will be present, the children are denied because there is not a numerical score there in front of him.

Now this problem is not exclusive to Down's syndrome in children. There are a number of disorders where this is a problem also, where there is going to be a high probability of retardation. And these children also have similar problems with SSI. The key concern we have with the denial itself is that these children are often missing out on services or care, such as speech therapy, physical therapy, home training, educational training, stimulation programs, and some basic medical care. And without these services, they do not receive the full opportunity to reach their potential. And also time is of the essence here. These services need to be started with these children as soon as possible.

When they are denied SSI and they appeal, SSI will come back and reimburse monetarily through back payments, but there is no way that they can come back and reimburse them for the time that is lost. It is irreplaceable. So therefore we obviously, feel that the presumption portion of the legislation is appropriate, justified and fair. We also serve a large number of children who are diagnosed with multiple medical problems that are multiply involved, and these children are often denied SSI benefits.

What I would like to do is give you two examples of children like this, and coincidentally, both of these children, if the presumption criteria had been in place, would have been approved for SSI on their initial application, but of course it was not in place. In all honesty they should have been approved anyway if their medical condition had been viewed on the whole and not on these individual aspects or components.

Now both of these children applied for SSI and appealed. They were turned down on both. They both went through appeal hearings. The first child was approved for SSI at an appeal hearing at which I testified, and this was approximately 1 year after her initial application. And the second child was denied at the appeal hearing and was approved only after a civil law suit was filed, approximately 2 years after her initial application and she yet this day has not received her back payments.

Both of these children were denied because their problems, their medical problems, were reviewed on an individual and separate basis. In other words when all the material was reviewed, each problem was looked at individually and on an individual basis the problems did not quite meet the SSI criteria for approval.

Let me give you some examples of the conditions of these children so you will have an idea what we are talking about. The first child was diagnosed with Trisomy X and this carries a probability of retardation, and she was also significantly developmentally delayed at the time of diagnosis which just increases the probability that she would be retarded. She had virtually no communication. She sat on the floor and screamed and cried virtually the entire day. She had hearing loss due to structural malformations within her ear. She obviously had speech delay. She had gastrointestinal problems and blockages that caused daily bloating, constipation, and a great deal of pain. She had malformations of her urinary tract which caused chronic infections, chronic urinary tract infections. She had gross motor delay due to bone defects within both her legs. She suffered from chronic upper respiratory infections, chronic ear infection, and she also had allergies.

Now obviously this entailed a number of hospitalizations and surgeries. She needed followup care and therapy and yet with all of these problems, she was denied SSI for 1 full year simply because each one of the problems was reviewed separately and there was never a consideration given to the child's condition or the child as a whole.

Another very similar example was a child diagnosed with Trisomy III-P. She also was significantly developmentally delayed at the time of diagnosis. She also had an immune system deficiency. She has a gastro-esophageal reflux. She had severe recurrent febrile seizures. She also had speech delay and motor delay. Obviously this child also endured a great number of hospitalizations and was in need of treatment. But here again, she was denied because each one of these problems was reviewed individually. And in reality that is just not the case.

If you had worked with these children and see them, you would know that each one of the problems interacts with the other. It affects the child. They all affect the child together as a whole and affect the family as a whole. They run simultaneously. The parents cannot treat one problem 1 day and think it is going to go away and then treat another.

Another example, the second child, her immune system deficiency made her more susceptible to illnesses which then caused severe febrile seizures which caused hospitalization. Also the immune system deficiency made her more susceptible to a number of illnesses, therefore it was hard for her to enter day programs. Thus, she could not receive some of the therapy that she needed to overcome her delays. So obviously, you can see that the total aspect of the child's illness should be considered and not each problem on its individual merits.

Also, I think it needs to be considered that the families of these children are undergoing incredible stress. Most of them have had a diagnosis recently that is devastating to a number of parents. There are daily medical problems, numerous hospitalizations in which they do not know if their child is literally going to live or die. And to add to this, the physical and mental stress of having to deal with SSI, and it is a stressful situation, it seems unnecessary.

The other component that we would like to talk about is outreach. Now we work with a number of area professionals in East Tennessee, head start teachers, day care teachers, public schools, health departments, in efforts to locate children with developmental delays and chronic medical problems. In doing this, we find a number of children who are eligible for SSI services, but do not receive those services simply because parents and/or professionals who are involved with the children did not realize that they met the approval criteria. Therefore, the children are going without some of the services and the benefits that SSI might give them.

We also run clinics for children and families who are already receiving SSI in which we try to talk with the families about any problems they are having with SSI in regards to medical followup, educational programs, speech therapy, any type therapies and try to coordinate with local agencies. We feel that if SSI were to institute an outreach program that they would be able to better educate some of the professionals that come in contact with these children, especially at a young age, and make them aware of what would be approval criteria for SSI so that they can pick up on some of these children.

We also think that, if possible, the SSI program could use outreach to teach applicants the proper way that SSI works or a better way to help facilitate the process. We think that this would help things run more efficiently and would allow for fewer requests or second requests for records. It would require that there be less reevaluations and it would require that there probably would be less appeals. Therefore, we think it would make the SSI program run more efficiently.

But again, I appreciate the opportunity to testify here today, and if you have any questions, I will be glad to try to answer them for you.

[The statement of Mr. Shelton follows:]

BEFORE A JOINT COMMITTEE OF THE HOUSE SELECT COMMITTEE ON AGING AND COMMITTEE ON WAYS AND MEANS SUBCOMMITTEE ON HUMAN RESOURCES

Testimony of William S. Shelton.

My name is William S. (Bill) Shelton and I am a social worker, and appearing on behalf of the University of Tennessee Developmental and Genetic Center. I have worked there as a social worker for approximately five and one half years. I handle the cases of approximately 40 children each month. I also coordinate the pre-school program through the Tennessee Department of Mental Health and Mental Retardation and coordinate Protective Services Counseling, Diagnostics and Evaluation.

In the course of my work at the Developmental and Genetic Center, I work with families who have children with serious medical problems. I come in contact with these families before they have applied for SSI, and while their applications for SSI for their children are pending. I understand that this committee is considering making changes in the SSI program that relate to children. I want to give you examples of the families I have worked with and their experiences with the SSI program. I will also make suggestions for changes, based on my experience and on the collective experiences of eight social workers and other staff members at the Developmental and Genetic Center at the University of Tennessee Hospital.

We worked with one family who lived in a very rural county, who had a two year old child with severe problems. When she first came to us, the child sat on the floor and screamed all of the time. We evaluated her and found she was delayed. After working with this child we discovered that she had chronic ear problems because the structure of her ear was not properly formed. She had gastrointestinal problems with pain and bloating after she ate. She had speech problems, recurrent urinary tract infections, visual delay and chronic severe behavior problems. Her hearing problem made it difficult for her to respond to those caring for her. After genetic testing, we discovered she had a chromosomal problem called Trisomy X. This disorder has a high probability of retardation and accompanying physical problems. This child's parents were conscientious and applied for SSI benefits for her and were turned down on their first application. We urged them to reapply, and they did so three months after their initial application was denied. They were again denied benefits. The family was not granted benefits for this child until eight months after their second application. A total of 11 months elapsed from when they first applied.

During this time, we did our best to see that this child was provided the services that she needed. We worked with this family to apply for crippled children's services in Tennessee. We also worked with this family to find ways to provide any services the child needed while waiting to get SSI benefits. Even though this child was ultimately approved, the application process put an incredible strain on this family. The strain of having a seriously ill child and the strain of having to apply and be denied and follow through on the application for SSI was very great for this family. It involved both the concern whether they would be able to provide the medical care and other services that their daughter needed as well as concern about the bills that were accumulating by providing the services.

Another family that we work with has a three-and-a-half-year-old child. This family applied for SSI in late 1988 and was denied in January 1989. They have not yet heard about their appeal of this denial. The medical records that we submitted on behalf of the child show, even though this child is three and a half years old, there is a year and a half delay in his development. Also, testing was done and his Stanford Binet scores roughly equate to an IQ score of 50, which is moderately retarded. As I understand it, an IQ of 50 is supposed to meet Social Security's requirements for eligibility. Still, he was denied SSI benefits. This child also has chronic reactive airway disease with asthma, bronchitis and pneumonia. His reactive airway disease seriously restricts his ability to be in certain environments. It does not allow him to receive the stimulation, training and educational therapy that he needs. Supplemental Security Income benefits could enable this parent to hire someone to come into her home to provide this child the services he needs. Fortunately, this child gets Medicaid. However, the family lives in a rural community and there are services that need to be provided to this child that cannot be obtained through Medicaid.

Our center sees a lot of children in East Tennessee. We have a child development grant to work with children under six years old. We follow up with families who have children with genetic abnormalities. We work very hard to try to identify children who are in need of services. For example, we contact school systems, Headstart programs and other places where children who are handicapped are likely to be found. We often advise families to apply for SSI for their children since they are unaware of the program. We also run a home based preschool program and have speech therapists and psychologists conduct home visits with our families in rural counties where it would be impossible for the families to come into Knoxville to get services.

In the course of our work with families and in doing outreach, we find that SSI is both a benefit and a frustration to families. We come into contact with many families who are unaware of the SSI program and we advise them about the program. We are unable to find all of the families that need our services or SSI for their children. We know there are families who go unserved because of their inability to get SSI and Medicaid.

It would be beneficial if outreach could be done in a more systematic way to advise families that they can apply for SSI eligibility for their children. If the Social Security Administration actually performed outreach services, it could provide information about other services to families that are identified.

When we advise a family to apply for SSI, we advise them to write down every single doctor their child has seen. Children with medical problems like the ones we see have many treating sources. Without some assistance in filling out the application form, the medical evidence that is gathered for children is often limited. The people deciding disability claims seem to limit their development of that disability claim to evidence that the parent lists is being available on the initial application form. The benefits of an outreach program by Social Security would be identifying potentially eligible children, helping fill out the application forms, and referring them to other services.

One of the most frustrating aspects of advising families to apply for SSI benefits for their children while they are infants is that there is a high probability they will be denied unless we can produce an IQ score. It seems that Social Security is only interested in the child's IQ. We often have clearly documented diagnostic testing to show that a child has a genetic abnormality. This genetic testing should make that child eligible. In our experience, these children are often denied. We even advise any family with a child diagnosed with Down's Syndrome, which causes the probability of retardation and accompanying physical problems, to expect to have to pursue appeals and possibly go to a hearing before being approved.

Other children, such as those diagnosed with genetic disorders like Fragile X, are denied the benefit of SSI until they attain the age that they can have IQ testing done that produces numbered scores. Fragile X is a problem that carries with it a high probability of mental retardation. Requiring children to have IQ testing in cases like these results in a substantial delay in the children's families receiving SSI and sometimes Medicaid for them. This delay makes it very difficult for families with whom we work to obtain services for the child.

It is very important for families and children who have very specific diagnoses which will result in disabling medical problems to be able to get SSI early and get early intervention. Our goal with these children is to help them reach their potential. For example, we may test a child and determine that that child's maximum functioning will be a sixteen year old's maximum functioning. Our goal is to help that child reach his potential. Without early intervention services, we cannot help children meet those goals.

Those who decide disability claims seem to be primarily interested in the child's IQ, even though a child may have a host of severe physical problems. Social Security appears to look at just the parts and not the sum of medical problems that affect an individual child. I have testified at children's SSI disability hearings before administrative law judges, and it is very frustrating to have to try to look at Social Security's listing of medical problems and fit a child into them. The child may have five medical problems all of which are on the list but none of which meet the severity required by the list. If you add the five medical problems together, the child is very seriously affected. However, if you look at each of them individually, they can't meet or equal a problem on the list. It is important for Social Security to look at how a child's medical problems affect the total child. The law should change to require considering the whole child in determining SSI disability.

The income from SSI is vitally important to families with seriously ill children. Much of the area that the Developmental and Genetic Center serves is rural. Individuals in rural communities have to overcome the barrier of transportation to receive services for their children. Without the money to pay for gasoline to come to Knoxville, families who are 40 miles away can't always get services for their children. Medicaid has its limits. There are some medications that are not covered by Medicaid and a family needs to pay for them. Many pharmacies don't provide families credit for that. There are some supplies that families need for their children that they are unable to get unless they have some additional money.

Also, families use their SSI money to improve the quality of their children's lives. One mother had a child who was unable to respond to direction. Because she got SSI money she was able to put a fence in her front yard so that the child could go out unrestricted and play in the front yard. Otherwise, this child's ability to get out and play in an open environment would have been absolutely restricted because of the danger to the child. Some families use the SSI money to pay for summer programs for children who need help and stimulation year around when the school systems don't provide services year round. These services are essential to these children because they help prevent them from regressing during the summer months.

Finally, one of the other difficulties not reflected by the bills that are being considered here today is what happens to families after they have been approved for SSI. If the family is on a fixed income, without income fluctuation every month, the child's SSI will be relatively stable. However, we also work with a number of working families who also qualify for SSI. If a working parent or parents have income that fluctuates from week to week, for example, an individual who works on minimum wage and whose hours may vary, then the child's SSI amount also varies. Because of the way Social Security deems income from the parent to the child, a family will have no idea how much their SSI will be or whether they will even get it or a Medicaid card each month. They are kept in a perpetual state of uncertainty. Even though they have carefully reported everything, Social Security may pay them too much and tell the family that they are overpaid and that they have to pay the money back. This problem presents a significant problem and a lot of anxiety for families of disabled children. We would recommend that you consider looking at the deeming problems that families have and of ways of alleviating those deeming and overpayment problems.

I appreciate the opportunity to testify before this committee and look forward to seeing needed changes for children in the SSI program.

Acting Chairman DOWNEY. Thank you, Mr. Shelton, very much for your testimony. Mr. Carozza.

STATEMENT OF MICHAEL C. CAROZZA, DEPUTY COMMISSIONER FOR POLICY AND EXTERNAL AFFAIRS, SOCIAL SECURITY ADMINISTRATION

Mr. CAROZZA. Thank you, Chairman Downey. I am happy to be here today to discuss the current status of the supplemental security income program and I would ask that my full statement be made a part of the record. In my remarks before you today, I would like to discuss the basic goals and objectives of the SSI program, the appropriateness of the income and resource levels, how and why disabled children are included under the program, and SSA's extensive outreach efforts.

The fundamental goal of the SSI program is to provide a basic level of income support to needy, aged, blind, and disabled persons based on national eligibility standards and payment levels. There are five basic objectives of the program that we try to provide. First, an income source of last resort. Second, nationally uniform eligibility requirements and benefit standards, and eligibility determinations that are based on objective criteria. Third, incentives for those who are able to work to become self-supporting. Fourth, an efficient and economical way to provide assistance. And fifth, encouragement to States to supplement the basic Federal benefits.

I believe the SSI program is a successful and effective program. It has provided and it continues to provide a very important element of the Nation's support system for aged, blind, and disabled persons, and it is meeting the goals that Congress has set for it. In calendar year 1988, SSI benefits totaled almost $14 billion; $11 billion of that was from the Federal Government and another $3 billion from the States.

Let me first address the appropriateness of the income and resource levels of the program. Benefit levels for an individual and an eligible couple are currently around 75 and 90 percent, respectively, of the poverty line. I believe this is appropriate when you consider that SSI benefits are intended to be an income source of last resort. States may supplement the basic Federal benefit and other Federal and State programs are available to provide cash and in-kind assistance to SSI recipients. Such programs include food stamps, Medicaid, and housing assistance programs. In fiscal year 1989, Federal expenditures for medical assistance, food and nutrition assistance, housing assistance, and direct cash payments to assist low-income individuals are estimated to be around $86 billion.

The SSI resource levels represent an appropriate compromise of some different goals. On the one hand, it is reasonable to expect people to use their own assets to meet day-to-day expenses before the Federal Government is asked to provide them with assistance. On the other hand, people do need to have a certain level of assets to provide for emergencies or other exceptional kinds of situations.

Also, a person should not have to dispose of resources that are related to basic needs, such as a home, household furnishings, personal effects, and a car. Thus, these are not counted in a person's resources under the SSI program. The levels of allowable resources, as I am sure you are aware, are now $2,000 for an individual and $3,000 for a couple.

To turn for a minute to the topic of disabled children. The Congress decided in 1972 to include disabled children under the SSI program. The reason was that children living in low income households are among the most disadvantaged of all Americans and they deserve special assistance to help them become self-supporting. The test of disability for a child under age 18 is different than for an adult claimant for SSI benefits. The child must have an impairment that meets or equals in severity an impairment that is listed in the regulations. No consideration is given to vocational factors of age, education and work experience because the Congress recognized that these children would not have had any attachment to the work force.

A child must generally meet the same resource and income requirements as a disabled adult. Again, because the SSI program is a program of last resort, the income and resources of a parent living in the same household are considered in determining the eligibility of the child. In 1987, we had about 290,000 children receiving SSI, about 10 percent of the total disabled population of SSI recipients.

I would like to take a moment also to address outreach efforts. Social Security has a longstanding and an ongoing commitment to outreach. Most of our activities are done in our field offices where our personnel work with organizations and individuals to assure that people understand the SSI program and that our agency is ready to assist them in becoming entitled.

We have improved and expanded our public information activities. We have enlisted the help of welfare agencies and advocacy groups to find potentially eligible people. We are also reemphasizing our efforts directed to the homeless, and my full statement details many of our outreach activities.

Finally, this agency is cooperating with the AARP's ongoing SSI outreach demonstration project. The AARP report on the first year of the project demonstrates, I think, that great work can be accomplished when private and public sectors work together to provide assistance to our fellow citizens.

So in conclusion, I would like to say that SSI is an effective safety net, providing the aged, blind, and disabled with a floor of income, the value of which is enhanced when combined with Medicaid, food stamps, and other forms of assistance. Resource levels are set to assure that some cushion exists against emergencies, but that people with adequate means use those means to provide for their needs before they seek publicly funded assistance.

Outreach efforts to bring the benefits of the program to the Nation's hardest-to-reach populations are ongoing. We believe that efforts to mobilize coalitions of national and local organizations to find this population are probably the most effective means to reach it, and efforts at this level should be encouraged.

Mr. Chairman, I would be happy to answer any questions that the committee might have.

[The statement of Mr. Carozza follows:]

STATEMENT OF MICHAEL C. CAROZZA, DEPUTY COMMISSIONER POLICY AND EXTERNAL AFFAIRS, SOCIAL SECURITY ADMINISTRATION

Chairman Downey, Chairman Roybal, and Members of the Subcommittees:

I am pleased to be here to bring you up to date on the Supplemental Security Income (SSI) program. I think it would be helpful, first, to provide a general overview of the SSI program and of the people it serves--particularly with regard to the elderly. Then, I will focus briefly on the appropriateness of the program's income and resource levels and how and why disabled children are included under the SSI program. Finally, I will address our efforts to enroll potentially eligible people. I have also included, as an appendix to my statement, a description of the basic design of the SSI program.

I want to say at the outset that I believe that the SSI program is a successful, effective program. It has provided, and continues to provide, a very important element of the Nation's support system for aged, blind, and disabled people. SSI is meeting the goals Congress set for it.

BASIC GOALS AND OBJECTIVES

The SSI program's fundamental goal is to provide a basic level of income support to needy aged, blind, and disabled persons based on nationally uniform eligibility standards and payment levels. The SSI program was designed to provide:

- an income source of last resort for the aged, blind, and disabled whose income and resources are below specified levels;
- eligibility requirements and benefit standards that are nationally uniform, and eligibility determinations based on objective criteria;
- incentives and opportunities for those recipients able to work to become independent and self-supporting;
- an efficient and economical method of providing this assistance; and
- encouragement to States to provide supplementation of the basic Federal benefit.

CHARACTERISTICS OF THE SSI POPULATION, INCOME LEVELS, AND EXPENDITURES

Demographics

In January 1974, the first month SSI benefits were paid, more than 3.2 million individuals received benefits. Approximately 3 million of those had received public assistance payments under State programs. From that initial month, the rolls increased to 4.3 million recipients by December 1975. Following this high point, the numbers gradually decreased until 1984 and then increased again. By the end of 1988, there were 4.5 million recipients. This level of participation continues in 1989.

The number of recipients in any given month, however, does not fully reflect the numbers of people who receive benefits during the year. During 1988, new applications resulted in the addition to the SSI rolls of about 549,000 recipients. Of these, about 155,000 were aged. Other people, who had been eligible but whose circumstances prevented payment for a short period, came back on the rolls. Some recipients became ineligible. The net result of all these actions is that, during calendar year 1988, some 4.9 million individuals received SSI benefits.

The number of recipients who are aged 65 or older has remained about the same since 1974. As of December 1988 there were 2 million recipients who were 65 years old or older. Of these, about 1.4 million were recipients who became eligible based on age. Another 573,000 recipients entered the rolls as blind or disabled recipients but are now aged 65 or older. Disabled and blind recipients under age 65 account for the remaining 2.5 million recipients.

Currently, almost 45 percent of all SSI recipients are over age 65. Of those who became eligible on the basis of age, however, 62 percent are aged 75 or older. Forty-one percent of this group are aged 80 or older.

Nearly two-thirds (64 percent) of all SSI recipients are women. Of the aged group, 75 percent are women. These percentages have changed little since the program began in 1974.

Fifty-two percent of all SSI recipients are white and 25 percent black. Persons of other races comprise 5 percent, while race was not reported for 18 percent. For the aged recipient population, 46 percent are white, 20 percent are black, 7 percent are of other races, while no racial characteristics were reported for the remaining 27 percent. These data also have not changed significantly since the program began in 1974.

Ninety percent of all SSI recipients live in their own households; that is, they live in their own homes or apartments, or they live in another's household but share living expenses equally with the other residents of the household. Of the aged, 91 percent live in their own households. Many SSI recipients who live in their own households, however, do not live alone.

Our administrative records do not identify which recipients live alone nor can we sort the incomes of those who might live alone from the incomes of other aged SSI recipients. However, based on the review of a small sample of case files, we have estimated that about 900,000 recipients aged 65 or older (45 percent) live alone.

The sample could not be used to provide the average amount of Social Security benefits received by SSI recipients who live alone, but we do have information, which I will provide in the following section, about the numbers of SSI recipients who receive Social Security benefits and the average amounts received.

Income

Social Security benefits are the primary source of all SSI recipients' other income. In December 1988 (as was the case in December 1987), about 71 percent of the aged SSI recipients and over 37 percent of the disabled and blind recipients received Social Security benefits.

In December 1988, the average income from all sources (excluding State-administered State supplements), including Social Security and federally administered SSI benefits, for all recipients aged 65 and older (including those who receive no Social Security benefits) was about $411 a month. The average monthly Social Security benefit for SSI recipients who received them was $292. The average monthly SSI benefit was about $188 (including federally administered State supplementary benefit amounts).

Only 12.4 percent of all SSI recipients (some of whom also receive Social Security) have unearned income other than Social Security benefits. This percentage has remained fairly constant since 1974. The average monthly amount of these other types of unearned income was $86, both in 1987 and 1988. The average amount of non-Social Security unearned income received by aged SSI recipients who received such income was just over $79 a month.

Of the total SSI population, 1.6 percent of the aged, 7.1 percent of the blind, and 5.7 percent of the disabled have earnings. Of those who worked, the average monthly earned income for the aged in 1988 was $176, for the blind $482, and for the disabled $162.

Expenditures

The total amount of Federal SSI benefits paid, not including State supplementary benefits, increased from $10 billion in calendar year 1987 to $10.7 billion in calendar year 1988.

Total expenditures by States for supplementary benefits have increased from nearly $2.9 billion in calendar year 1987 to $3 billion in calendar year 1988.

INCOME LEVELS

Since the beginning of the SSI program, there has been discussion about the Federal benefit standard. The SSI benefit levels for an individual and for an eligible couple have been around 75 and 89 percent of the poverty line for one- or two-person households, respectively, since the program began in 1974. The effect of the exclusion from income of $20 a month of any unearned income the recipient gets would have the effect of narrowing the difference between the SSI benefit levels and the poverty line by about 4 percentage points.

State supplementary benefit amounts further close the gap. In three States--Alaska, California, and Connecticut--SSI and State supplementary benefits provide income levels above the poverty line for one-person households. Eight States--the three that have already been named and Colorado, Massachusetts, Oklahoma, Rhode Island, and Wisconsin--provide supplements to SSI for eligible couples that raise income levels to above the poverty line for two-person households.

Also, of course, benefits under other Federal programs are available to SSI recipients. For example, when the value of food stamps is added to the basic Federal benefit standard, the recipient's effective purchasing power is substantially increased. Using the 1988 poverty line and SSI benefit levels, an individual who has a small Social Security benefit and is also eligible for SSI in a State that does not offer any supplementary benefits had total cash income of $374 a month in 1988. Based on that level of income, the individual could get food stamps with a minimum value of $10 a month (or a maximum of $90 a month) under the Thrifty Food Plan. His total income would then have been between 81 and 96 percent of the poverty line. An eligible couple, in the same circumstances, would have had total cash benefits of $552 a month plus between $30 and $165 a month under the Thrifty Food Plan. The couple's total income would have ranged between 98 and 122 percent of the poverty line.

SSI recipients also are categorically eligible for Medicaid in most States. While this coverage does not provide assistance in meeting normal daily needs, it does prevent the need to use scarce income and resources to obtain health care. Low-income housing and rent subsidies under Federal housing assistance programs are other sources of assistance that help make the cash assistance go further toward meeting basic needs.

RESOURCE LEVELS

The SSI resource test is one of the eligibility requirements designed to measure an individual's need for SSI assistance. In setting such an eligibility requirement for a cash assistance program like SSI which is funded by general revenues, it is reasonable to expect people to use their own assets to meet day-to-day expenses before the Federal Government is asked to provide them with income assistance. However, it is recognized that people need to have a certain level of assets to provide for emergencies or other unusual or nonrecurring expenses that cannot be met from the basic monthly benefit.

SSI law sets limits on the value of resources a person can own and still be eligible for SSI. What constitutes a resource for SSI purposes is defined by regulations as cash or other liquid assets or any real or personal property that an individual (or spouse) owns and could convert to cash to be used for his support and maintenance. If the individual has the right, authority, or power to liquidate the property, or his share of the property, it is considered a resource. Thus, even though a person may own something, if a property right cannot be liquidated, the property will not be considered a resource. Finally, in determining the amount of resources that are counted, only the amount of the resource that represents the individual's equity is considered.

Although the law does not state what a resource is, it does provide that, in determining whether an individual's resources are within eligibility limits, the value of certain resources will be wholly or partially excluded from countable resources. When the exclusions from resources are taken into account, the resource levels above which SSI eligibility is precluded are not so limiting as the dollar amounts might suggest. The value of things that most people own that are related to basic needs is not counted toward the limits (i.e., a home, household furnishings, personal effects, and a car). In most cases when a person's resources cause ineligibility for SSI it is because the value of bank accounts and nonexcluded real property exceed the resource limits.

The resource limits have increased gradually since 1985 and now are $2,000 for an individual and $3,000 for a couple.

Most SSI recipients have very little in resources. In fact, only about 7 percent of aged recipients had resources of $1,500 in 1986, when the limit was $1,700. Further increases in the resource levels will help only those whose financial situation now prevents or delays their becoming eligible for public assistance. The higher the level, the greater becomes the question of the appropriateness of providing publicly funded assistance to people who have the resources to provide for themselves.

DISABLED CHILDREN UNDER THE SSI PROGRAM

When the Congress established the SSI program in 1972, it included disabled children under the program. The reason for doing so, expressed in the legislative history accompanying the legislation, was that disabled children living in low-income households are among the most disadvantaged of all Americans and deserving of special assistance to help them become self-supporting members of society. The intent was to make it possible for disabled children to get benefits under the SSI program, rather than under programs for families with children, because the needs of disabled children are greater than those of nondisabled children.

The law requires that to be considered disabled under the SSI program, an individual must be unable to engage in substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last at least 12 months. In the case of a child under age 18, the law requires that there be a medically determinable physical or mental impairment of comparable severity to that which would be considered disabling for an adult.

The definition of disability for a child is different from that for an adult claimant for SSI benefits--the child must have an impairment that meets or equals in severity an impairment in the Listing of Impairments in the regulations. If the severity of an adult's impairment does not meet or equal the severity of an impairment in the Listings, he can still be found disabled if his impairment prevents him from doing any substantial gainful work that exists in the national economy, considering his vocational factors (age, education, and work experience). Children are not considered under this vocational test because the Congress recognized that they would not have had any attachment to the workforce.

In addition to meeting the definition of disability, a child must generally meet the same resource and income requirements as a disabled adult. The income and resources of a parent living in the same household as the child under age 18 are considered in determining the child's eligibility and payment amount. Regulations provide for deeming the parent's income and resources to the child after allocating some of the parent's countable resources to the parents and some of the parent's income to the parents and other minor children in the home.

The number of disabled children receiving SSI benefits has grown by 171 percent since 1975. In that year, 107,026 children received SSI. This number represents about 5.3 percent of all disabled SSI recipients. By 1987, this number had grown to 290,256 recipients, representing almost 9.6 percent of all disabled SSI recipients.

In December 1987, almost 49 percent of children who were SSI recipients were disabled by some form of mental disorder. Of this group, close to 43 percent were mentally retarded. Some 25 percent of children on the SSI rolls are disabled by diseases of the nervous system and sense organs; another 10 percent are disabled by congenital anomalies.

OUTREACH EFFORTS

Our field office managers, field representatives, and claims representatives meet with all manner of organizations in their service areas to talk about SSI and other programs administered by the Social Security Administration (SSA). These activities are the foundation of SSA's longstanding, ongoing commitment to outreach. Their work in this area assures that people learn about their potential eligibility for benefits under programs administered by SSA and that they understand that SSA is ready to assist them in becoming entitled.

SSA field offices whose service areas include large non-English speaking populations either have staff who can translate or make arrangements with community organizations that can provide translators. In every service area where there is a significant Spanish-speaking population, SSA offices have staff who speak Spanish. In service areas where there are large concentrations of Chinese people, SSA offices have staff who can deal with Chinese dialects. In service areas where there are few non-English speakers or where the foreign language encountered is uncommon and, to the field office's knowledge, there is no one in the community who can provide translation services, SSA staff advises individuals that they should be accompanied to the SSA office by someone they know who can translate for them.

To enhance its day-to-day outreach efforts, SSA is continuing its efforts to improve and expand its SSI public information activities. Our efforts are focused in several directions, one of the most important of which is to establish liaison with national, State, and local legal and welfare agencies and advocacy groups to tell them about the SSI program and enlist their assistance in finding potentially eligible people. SSA's efforts include:

- providing field components with model presentations and a supporting universal slide series so they can tailor a speech about the SSI program to the needs of outside organizations;
- providing field components with monthly public information packages containing information about the SSI program (packages include news releases and scripts for radio and TV spot announcements suitable for local media use in Spanish and English);
- sending organizations with an interest in the SSI program a quarterly SSI Information Item Newsletter containing articles for them to publish in their own newsletters and bulletins;
- redesigning and revising publications and other printed materials for current and potential recipients to incorporate graphic techniques and to simplify the language;
- preparing and distributing posters explaining basic SSI eligibility requirements (these posters were placed in 39,000 post offices nationwide as well as in the offices of organizations that provide services to low-income aged, blind, and disabled); and
- encouraging regional outreach efforts.

SSA is also reemphasizing its efforts with regard to the homeless. The homeless outreach efforts include:

- appointing a homeless coordinator to be the focal point for all claims and postentitlement activity relating to the homeless in each field office where such a position would be appropriate;
- encouraging district and branch managers or other appropriate field office staff to serve on interagency health and welfare councils serving the needs of the homeless;
- assuring that local staff "network" with private nonprofit community and religious organizations serving the needs of the homeless;
- assuring that all appropriate individuals are aware of the relatively new provision for continued receipt of full SSI benefits for certain individuals temporarily institutionalized in public or private medical facilities;
- publicizing to shelters the relatively new provision for continued receipt of SSI benefits for 6 months in any consecutive 9-month period for persons who are residents of public emergency shelters; and

- o assuring that appropriate individuals are aware that there is no offset against SSI benefits because of receipt of charitable gifts based on need, from nonprofit organizations, of items such as meals from soup kitchens, clothing and shelter.

In addition, SSA is preparing a series of "best practices" issuances which describe projects dealing with the homeless and other categories of hard-to-reach people which are working well in one setting and have potential for proving successful in another. These issuances should allow SSA offices and other service providers to give active consideration to practices that have already been proven in other areas.

SSA is also developing a videotape for providers of service and SSA's field staff to assist the service providers in understanding SSI eligibility requirements and the way SSA takes and processes claims.

American Association of Retired Persons' (AARP) SSI Outreach Project

Under a grant from the Commonwealth Fund, the AARP is conducting an ongoing SSI outreach demonstration project designed to increase participation in the program. SSA, along with the Administration on Aging, cooperated with the AARP in its efforts to seek out and enroll aged persons who are eligible for, but not receiving, SSI benefits.

Last year outreach demonstrations took place in Pittsburgh, El Paso, and Oklahoma City. Each project was cosponsored by the local area agency on aging with assistance from senior centers, local nutrition programs, hospitals, and a variety of community service groups. SSA field offices also cooperated with local area agencies on aging in the outreach demonstrations.

SSA actively participated on AARP's Technical Advisory Committee, as well as in the local SSI "coalitions" in El Paso, Oklahoma City, and Pittsburgh. SSA contributed to the demonstration's project design, provided critical information on site selection, trained outreach workers, and provided the data necessary to evaluate the project.

On behalf of Social Security Commissioner Dorcas R. Hardy, I would like to extend congratulations to everyone involved who contributed to the first year of the project. It demonstrates the great work that can be accomplished when the private and public sectors join together to help our fellow citizens.

The AARP's final report on the first year of their demonstration outreach project indicates that their effort produced a substantial increase in both SSI applications and awards of benefits. Although this first phase provided no clear indication of the magnitude of the unreached population, it did establish that the type of outreach activities used should be pursued further in an effort to make SSI benefits available to as high a percentage of the eligible population as possible. In fact, that is precisely why SSA has proposed to cosponsor 2 of the 10 sites that the AARP is planning to include in the second year of its SSI outreach project.

Special SSI Outreach Efforts

The Social Security Amendments of 1983 required ongoing outreach activity to potential Social Security beneficiaries at the time they were notified of their upcoming eligibility for Supplementary Medical Insurance under Medicare.

Since July 1983, each month approximately 110,000 potential beneficiaries have been notified about the SSI program and its eligibility requirements at the time they receive notification of eligibility for Medicare.

It is estimated that the ongoing outreach effort has resulted in about 2,000 awards to the elderly per month since July 1983, when the provision became effective. This is almost 2 percent of the 110,000 notices sent each month.

Our experience with outreach efforts--such as the one-time "SSI Alert" and the ongoing monthly mailing to people nearing age 65--which are based on a match of administrative records with limited screening criteria is that these methods can be somewhat effective in locating potential SSI recipients. However, our conclusion is that these methods should not be viewed as the only ways to reach potential SSI recipients.

CONCLUSION

SSI is an effective safety net, providing the aged, blind, and disabled with a floor of income, the value of which is enhanced when combined with Medicaid, food stamps, and other assistance.

Resource levels are set to assure that some cushion against emergencies exists, but that people with adequate means use those means to provide for their needs before seeking publicly funded assistance.

Outreach efforts to bring the benefits of the program to the Nation's hardest-to-reach populations are ongoing.

SSA is committed to providing high-quality service to its clientele. A major part of that commitment is bringing the SSI program to the people for whom it was designed. Our outreach efforts over the years and the special mailings have not resulted in our finding the number of potential eligibles that others have estimated exists. We believe that efforts to mobilize coalitions of national and local organizations to find this population are probably the most effective means to reach it, and efforts at this level should be encouraged.

Mr. Chairman, I would be happy to answer any questions.

SSI PROGRAM DESIGN

SSI standards include age 65 as the minimum age requirement for assistance based on age, and nationally uniform definitions of disability and blindness which are basically the same as those used for insured workers under the Social Security disability insurance program.

The SSI program is intended to be the nation's income assistance program of last resort. Therefore, in order to remain eligible for SSI, recipients are required to apply for payments from all other public or private programs for which they may be eligible.

The SSI program is designed as an objective, flat grant system. Under flat grant systems, assistance amounts are determined by subtracting countable income from a standard benefit rate. In keeping with its flat grant design, the SSI program has uniform limits on the dollar amounts of income and value of resources that a person can have and qualify for Federal assistance. Currently the monthly income limits--which correspond to the Federal benefit rates--are $368 for individuals and $553 for couples. In January, just as with Social Security benefits, the SSI benefit rates are adjusted automatically to reflect increases in the Consumer Price Index.

When Congress created the SSI program it was with the expectation that some States would supplement the basic Federal payment to maintain payment levels higher than the Federal SSI standards. The Congress provided that the Federal Government could agree to administer a State's supplementary payment program. Under these agreements, the Federal Government absorbs the administrative costs of the State's program. Currently, the optional State supplementary payment programs of 16 States and the District of Columbia are administered by the Federal Government. Congress also required that States pass along the cost-of-living increases in the Federal benefit rates.

The law provides certain exclusions from income and resources, and only the value of income and resources after the exclusions are applied is counted in determining eligibility and the benefit amount.

Some of the principal income exclusions are the first $20 of any monthly income; the first $65 plus one-half the remainder of monthly earned income; cash assistance provided under a wholly State or local government funded, needs based program; Federal disaster assistance; and small amounts of irregularly or infrequently received income.

The current resource limitation is $2,000 in countable resources for an individual and $3,000 for a married couple living together, whether or not both are eligible for SSI. As with income, not all resources are counted. The law excludes:

- the home (and the appertaining land) regardless of its value;
- household goods and personal effects of reasonable value (equity of $2,000 or less, by regulations);
- an automobile (by regulation, of any value if it is used for employment, needed to obtain medical treatment, or modified for the use of a handicapped person, or, if none of the preceding applies, up to $4,500 market value);

- property essential to self-support;
- for the disabled and blind, resources essential to a plan for achieving self-support;
- life insurance policies, if the total face value of all policies on any person does not exceed $1,500 (term life insurance is not a resource);
- burial spaces regardless of value;
- funds set aside for burial the amount of which does not exceed $1,500 (at the time SSI eligibility begins) each for an individual and his spouse; the $1,500 is reducible by the face value of any excluded insurance policy and the value of any irrevocable burial arrangement the individual has; the excluded fund may exceed $1,500 by the amount of interest accrued after SSI eligibility begins;
- retroactive SSI and Social Security benefits for 6 months after receipt--or for 9 months, if the retroactive benefits are received in the period beginning October 1987 and ending September 30, 1989;
- amounts representing conserved disaster assistance, including any interest earned by such amounts; and
- the value of shares of stock in regional or village corporations owned by natives of Alaska as provided in the Alaska Native Claims Settlement Act.

In addition to the exclusions in SSI law, other statutes exclude certain payments made under those statutes from being counted toward the SSI resource Limits. Generally, these exclusions apply to relocation assistance, judgment payments to Indians, nutrition assistance, education grants and loans, housing assistance, etc.

Chairman ROYBAL. Thank you, Mr. Carozza. Mr. Pollack.

STATEMENT OF RONALD F. POLLACK, EXECUTIVE DIRECTOR, THE VILLERS FOUNDATION

Mr. POLLACK. Thank you, Mr. Chairman. Thank you for the opportunity to testify as part of this hearing on alleviating poverty among older and disabled Americans and how the Supplemental Security Income program can be strengthened toward that end.

I am sure I need not tell members of this panel about the persistence of poverty among our older population. Clearly over the years we have made much progress. The proportion of the elderly persons who are below the poverty line has been reduced from one out of three in 1959 to approximately one out of eight in 1987. The success is due largely to improvements in both the coverage and benefits of the Social Security program. But some sobering facts still remain.

The number of older persons with incomes below the poverty line, approximately 3.5 million, has actually increased slightly over the past 3 years. The poverty rate among elders is the highest among all adult age groups. Only the national disgrace of poverty among children occurs at a higher rate.

Aged poverty disproportionately affects numerous and significant subgroups of the aged population—women, minorities, and the old-old. For example, for older women, the poverty rate in 1987 for older black women was over 40 percent. More than two out of five elderly black women had incomes below approximately $5,500 for the year.

One of the most significant facts and the reason SSI is so important relates to the persistence of poverty for those who happen to be poor when they are old aged. We know that, for the elderly, if you are poor the likelihood of you being chronically poor is much higher than it is for other populations. Even though the elderly comprise only approximately 12 percent of the overall population, they comprise approximately 33 percent of the population that is chronically poor.

What I mean by the term "chronically poor" is those persons who, over a 10-year period, have experienced poverty for at least 8 of those 10 years. And why is that? Well, to simplify matters, for those who take a look at the question of poverty and strategies available to get out of poverty, essentially two things work better than anything else: one is opportunity for employment and the other one is marriage.

With respect to the elderly, both of those strategies are the least applicable to them compared to other portions of the population. And hence, it is important to take a look at a safety net program like SSI because other opportunities that may exist for some folks who are temporarily poor are less available for those who are going to be chronically poor, specifically the aged.

The SSI program provides us with a wonderful framework by which we can deal with poverty amongst the elderly. Benefits are universal and are adjusted each year for inflation. Eligibility standards are uniform and are national. By and large, SSI also provides a very important benefit; namely, Medicaid benefits are provided for those people who are going to receive SSI assistance.

Now let me give you one brief set of statistics about how important that is for somebody below the poverty line who may also be receiving Medicare assistance. In the Medicare program, the cost-sharing that exists under that program has risen dramatically over the course of this decade. The part A deductible has risen from its rate of $180 at the beginning of 1980. Today it is $560. The part B premium at the beginning of this decade was $114. Today it is $383. If you take a person who merely has one hospitalization, the out-of-pocket cost for somebody not receiving Medicaid comes out to over $1,000. Now those are the rock bottom costs that a person is going to pay. The total is approximately $1,018—$560 for the part A deductible, $383 for the part B premium, and $75 for the part B deductible. That total does not include part B coinsurance. It does not include excess billing by physicians. It does not include prescription drugs and it does not include uncovered services. Thus, for somebody below the poverty line, that rock bottom cost of just the part A and part B deductible and the part B premium is approximately 20 percent of their overall annual income.

Now to some extent this problem is going to be alleviated, we would hope, as a result of Medicare catastrophic coverage legislation that was enacted last year. One of the good things about the catastrophic bill that I thought was a very important improvement was the so-called buy-in protection that the legislation is supposed to provide to folks with incomes below the poverty line.

In a report that we will release next Wednesday, you will find that the implementation of this very important legislation leaves a lot to be desired. The legislation certainly provides a very important right in terms of providing coverage for these out-of-pocket expenses that the Medicare program requires, and that Medicaid is now supposed to be picking up. In reality, as our report will show next Wednesday, that coverage is failing to actually be translated to benefits on the local level for the vast majority of people for whom it was intended.

Now what can we do to strengthen the SSI program? What are its major failures? I will focus on three particular facets.

First, the benefits in the program obviously are too low. The Federal maximum fall substantially below the poverty line. In 1989, the maximum Federal SSI benefit for an individual, living alone, is just $368 per month or approximately 75 percent of the projected 1989 poverty line.

I must say I am surprised when I hear previous witness say that for a program of last resort, that is an income that is adequate for persons. We are talking about an income roughly translated on a weekly basis to $85 a week. Now if that is viewed as sufficient income, as a benefit of last resort, I would invite anyone who says that to join with me in living on that budget and say the same thing after they have gotten off that budget.

SSI funding structure permits States to implement Federal benefits and to provide necessary supplementation, but unfortunately only 26 States, plus the District of Columbia provide such supplementation. Even among those States, the median SSI supplement for an elder living alone is only $36 per month and, since 1975, the real dollar purchasing power of the supplement has eroded by more than half. Only four States—Alaska, California, Connecticut, and Massachusetts—provide supplements to elderly persons in amounts which, when added to the Federal benefit, result in income above the poverty line. Indeed, unless Massachusetts increases its supplement, unfortunately beneficiaries there will fall below the poverty line as well.

Second, the next major shortcoming in the SSI program is its low resource limits. An elder cannot qualify for SSI benefits unless he or she has extremely limited countable assets, not more than $2,000 for an individual and $3,000 for a couple in 1989, which is just over half the amount of the 1974 levels when the program was established in real dollar terms. According to a recent report from the nonpartisan Urban Institute that erosion alone has squeezed almost a quarter million persons out of the SSI eligibility ranks on the grounds that they have too many resources.

Third, partly because of inadequate benefit levels, but in large part out of ignorance and failure to have adequate information about the program, only about half the people who are eligible for assistance, even under these meager eligibility standards, are currently participating. A background paper released earlier this year, prepared for the AARP and the Commonwealth Fund Commission on Elderly Living Alone, confirms earlier estimates that only about half, 51.5 percent, of those eligible for SSI are actually receiving such benefits.

To this I might add, Mr. Chairman, that in the next month we will be releasing a report of a survey that we have undertaken in 19 communities across the country. I will not suggest that this survey that we have undertaken is a scientific sample of the SSI population; however, it involves a sample of many thousands of people in 19 very disparate communities around the country.

What we have learned from that survey, I think, is very instructive. We have learned that a fair number of those surveyed did not even know that SSI could increase one's income. An overwhelming majority of those surveyed believed that employed persons felt that they would not be eligible for SSI because they were employed. Most indicated that they believed owning a house would disqualify them for SSI. Many of those surveyed thought the person who received Social Security benefits cannot receive SSI. Only a small percentage of those surveyed knew that applying to receive SSI would also lead to eligibility in the Medicaid program. And a significant percentage indicated that they had no idea about how or where to apply for SSI benefits.

When we went to congregate meal sites and when we asked social service agencies about the adequacy of outreach efforts that were undertaken, we also learned a great deal. Three out of five persons surveyed reported that they had never heard a presentation about the SSI program. We conducted interviews in 31 Social Security district offices and, in those Social Security offices, when we questioned personnel there, very few felt that outreach presentations were being made each year on SSI. Regrettably those presentations that were made were not necessarily at low income sites.

SSA appears to make very limited use of television and radio to reach out to people. Indeed SSA district managers in all but 3 of the 31 districts offices that were visited felt that outreach efforts are inadequate for the task at hand. I suggest that there is a great deal that we can do. We understand the obstacles in making these improvements, particularly with respect to increasing benefits because of the cost. But we are very heartened by the fact that Chairman Roybal and Congressman Matsui have introduced legislation, both cosponsored by Chairman Downey. We think they are good pieces for discussion and analysis. We think parts of them can go forth responsibly within the fiscal constraints of the day.

And I would be delighted to talk about that further.

[The statement of Mr. Pollack follows:]

SSI IMPROVEMENTS: THE CASE FOR ACTION

Testimony by

RONALD F. POLLACK
Executive Director
THE VILLERS FOUNDATION

before the

SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS

and the

SELECT COMMITTEE ON AGING
U.S. HOUSE OF REPRESENTATIVES

Washington, DC
Thursday, March 2, 1989

Mr. Chairman -- and Mr. Chairman -- and members of the panels, thank you for giving me this opportunity to testify as part of this important hearing on alleviating poverty among older and disabled Americans and how the Supplemental Security Income (SSI) program could be strengthened toward that end.

Since our Foundation's principal concern and experience is with low-income elders, most of my remarks will focus on that group.

It's likely that no one on this joint panel needs to be convinced of the persistence of poverty among our older population. Clearly, over the years we have made much progress: the proportion of elderly persons afflicted with poverty has been reduced from well over one out of three in 1959 to just under one out of eight in 1987. That success is due largely to improvements in both the coverage and benefits of the Social Security program. But some sobering facts remain:

* The number of older persons with incomes below the poverty line -- about 3.5 million -- has actually increased slightly in each of the last three years, and hasn't declined significantly in more than a decade.

* The poverty rate among elders is the highest among adult age groups. Only the national disgrace of poverty among American children occurs at a higher rate.

* Aged poverty disproportionately affects subgroups -- women, minorities and the so-called "old-old." For older black women, for example, the poverty rate in 1987 was an astonishing 40.2%.

So the problem of poverty among older people persists, like an unwelcome guest.

Over the long term, it is hoped, rising real wages in jobs covered by Social Security will yield higher social security benefits and, eventually, eliminate the haunting spectacle of older people living on sub-poverty-line incomes. The Supplemental Security Income program -- SSI -- has been the vehicle suggested by most of us concerned about elderly poverty, as the way to deal in the relatively short term with this problem.

SSI has paid cash benefits to low-income aged, blind and disabled persons for a decade and a half. Some 4.2 million persons participate, about half of them over the age of 65.

Since its beginning in 1974, SSI has done enormous good. But it has not, as many thought at the time, made a dent in poverty among the elderly. In fact, since SSI began paying benefits in 1974, the elderly poverty rate is virtually unchanged, having declined only from 14.6% to 12.2% in 1987.

Members of these panels have heard compelling testimony about the nature of life at the sub-poverty level represented by the federal SSI benefit standard. The continuation of this pocket of poverty, in the midst of our enormous national wealth, is inexcusable.

But if SSI's benefit levels are inadequate, its structure gives reason for hope. The benefits are universal (though States can choose to supplement them). They are adjusted each year for inflation. Program eligibility standards are uniform and national. Perhaps just as important is the fact that, in all but a few states, SSI eligibility carries with it automatic eligibility for Medicaid. This is of the highest importance, given the fact that only 36% of elders in poverty are now enrolled in Medicaid, at a time when out-of-pocket costs for their health care are skyrocketing.

For these older Americans -- numbering more than two million -- health care costs are simply unaffordable. The current minimum cost if a Medicare beneficiary is hospitalized is $1,018 -- and that covers only the Part A and Part B deductibles and the Part B premium. Not included are Part B coinsurance, excess billing by physicians, prescription drugs and other uncovered services. But even the base amount of $1,018 constitutes almost one out of five dollars of their total income.

Eventually, most of these persons will become eligible for the Medicare "buy-in" that Congress, I am happy to note, included in the Medicare catastrophic legislation. But implementation of that new provision has been spotty, and it will not be fully phased in until 1993.

If the strengths of the SSI program are real, its shortcomings are well known, also.

First, its benefit levels are too low. The federal maximum falls substantially below the poverty line. In 1989, the maximum federal SSI benefit for an elderly individual is just $368 per month, or approximately 75% of the projected 1989 poverty line. For elderly couples, the maximum federal benefit level is $553 per month, or about 90% of the projected poverty line.

SSI's funding structure permits states to implement federal benefits. Only 26 states (and the District of Columbia) do so. Even among those States, the median SSI supplement for an elderly person living alone is only $36 a month -- and since 1975 the real-dollar purchasing power of that supplement has eroded by more than half. Only four states (Alaska, California, Connecticut and Massachusetts) provide supplements to elderly individuals in amounts which, when added to the federal benefit, result in incomes above the poverty line. And unless Massachusetts increases its supplement, beneficiaries there will fall below the poverty line as well.

The second major shortcoming in SSI is its low resource limits. An elderly person cannot qualify for SSI benefits unless he or she has extremely limited "countable assets":

not more than $2,000 for an individual and $3,000 for a couple in 1989 -- just over half the amounts of the 1974 levels, in real terms. According to a recent report from the non-partisan Urban Institute, that erosion alone has squeezed almost a quarter million persons out of the SSI-eligible ranks, on the grounds that they have too many resources.

Third, partly because of its inadequate benefit levels, but in larger part out of ignorance, participation in SSI even among those now eligible continues to be abysmal. A background paper released earlier this year, done for AARP and the Commonwealth Fund Commission on Elderly People Living Alone, confirms earlier estimates that only about half (51.5%) of those eligible for SSI actually receive benefits.

Our Foundation has been exploring this problem in modest ways.

For the last two years our Massachusetts office has run a small SSI outreach effort aimed at three specific immigrant communities in Boston. And last summer, grants were made to groups in more than a dozen states, to allow them to test the extent of knowledge about SSI among lower income seniors. Formal results are expected from both effortts in the next few weeks, but familiar trends are emerging as we begin to look at results: yawning gaps in awareness and understanding of SSI by low-income elders; inadequate outreach by SSA, especially among those most likely to be eligible; inadequate stafdfing at social security offices and, where people actually tried to get benefits, formidable procedural barriers to their success. All of these problems seem to be worse if language is added to other barriers.

The remedies for these shortcomings are simply stated, but not simply achieved.

First, increase federal benefit levels, at least to the federal poverty line.

Second, restore the asset levels to their real value at the time the program began. This would mean slightly more than doubling them from current nominal levels.

Third, mandate a major outreach initiative, using both SSA itself and private organizations with easier access to target populations.

All of this, I dare to say, is probably very familiar to the members of these panels. The obstacles to action are formidable: these remedies are expensive, and there has been no organized constituency pushing for these changes.

But, while there is no way to alter the ultimate cost of these improvements, it is easy to devise ways to phase them in so that the budget impact is not pushed beyond the realm of the possible.

And as for the question of a constituency, there are some encouraging signs:

* a growing number of national organizations -- religious and women's groups, labor, aging and disability organizations, among others -- are expressing greater interest in highlighting this need.

* many local groups exposed to SSI's inadequacies for the first time through their work with us last summer, are truly excited about trying to plug some of the gaps.

- a major new documentary on SSI and the elderly poor will air on public television stations across the country later this month.

- a national invitational conference on the problemhas been scheduled for next month, sponsored by our Foundation and AARP, in cooperation wioth the National Council on the Aging, the National Caucus and Center on the Black Aged and the Brookdale Center on Aging at Hunter College of New York.

Most significantly, of course, there is this joint hearing, and the important new bills introduced by Chairman Roybal, and by Rep. Matsui, both cosponsored by Chairman Downey. Together they send a signal that responsible, importantly positioned legislators are seriously concerned about poor elderly and disabled Americans, and intend to do something about it. I know these bills will be the focus of much activity in the months ahead.

This is not to say that passing this legislation will be easy; none of us is naive about that. But with the heightened level of Congressional interest, and the growing awareness of the problem in the country, I believe that we can look realistically at a down payment, at least, on the debt of conscience America owes to its poor older and disabled citizens.

Thank you very much.

Acting Chairman DOWNEY. Thank you, Mr. Pollack. Mr. Carozza, do you really believe that SSI is adequately meeting the needs of low income elderly and disabled people?

Mr. CAROZZA. Chairman Downey, I think we have to look at the whole range of programs that the Federal and State Governments offer to low income people. SSI is one program. On the Federal level, as I said, we are spending about $11 billion for SSI. I think the House Budget Committee put together a list of the programs in the budget that address the needs of high priority low income groups, and their total is somewhere between $120 and $130 billion. So SSI is just one component.

We have programs for medical assistance, for food assistance, housing assistance, and I do not think that SSI was ever intended to fulfill every need of every person.

Acting Chairman DOWNEY. What happens in the cases where it has to fulfill every need of every person, where there may not be something like food stamps? I cannot spend my health insurance to buy food or to pay for my shelter. Health insurance helps me. Medicaid does if I am sick, but it does not do much good for me if I am not.

The statistics that I have seen indicate that very few of the people on SSI, and I do not know what the percentage is off hand, are in publicly supported housing or receive some sort of assistance under a low income energy program. A lot of these people are just out there trying to make ends meet on $12 or $13 a day. It just does not seem to me to be enough, and I am curious about your perspective.

We take into consideration everybody else, but for the significant number of elderly and disabled who are living on this amount alone, it is not enough, is it?

Mr. CAROZZA. I think it is indeed very difficult. That is why when somebody comes into a Social Security office and we take an application for SSI, we also try to get them referred to all of the other programs that are available.

Acting Chairman DOWNEY. Let us talk about that for a minute. This question of eligibility and outreach. You just heard what Mr. Pollack said with respect to the study, and that will be public next Wednesday. We will certainly want to see that, and we may even want to have a hearing on it. Do you think that SSA is doing enough with respect to making people aware that this program is available to them?

Mr. CAROZZA. Mr. Downey, we can always do more. In fact, we are trying to do more. Let me give you a few examples, some of them are in my testimony. But Mr. Pollack mentions we do not make enough use of TV. One of the things that we have in production right now is a training tape, not for SSI eligibles or potential eligibles, but for the people like Mr. Shelton who come into contact with those people. What we seek to do is to explain to them that the SSI program is available and to let them know what the eligibility requirements are and what kind of documentation people need to get into the program. We are aggressively promoting the tape.

Another way that we are trying to reach more people is through our field office staff. I am surprised to hear that our district office managers feel that our efforts are inadequate, because we are trying to get our district office managers to get more involved in efforts to assist these people. I think that the best way to pursue outreach is not for our staff to do it directly. I think a Government agency is sometimes very imposing for people who are mentally ill, or disabled. What we would like to do is to work very closely with the volunteer agencies and advocates who see these people on a day-to-day basis and who have their trust. If they could feed these people in to us I think there is great potential there.

Acting Chairman **Downey**. What about the asset requirements. It seems to me that they have not kept pace with inflation over the years. Do you think there is any remedy there for us? Should we raise the asset test a little higher?

Mr. **Carozza**. The asset test was raised recently. We have not seen a really big jump in the number of people participating in SSI because of that. And I think what happens is that when you raise the asset test, you are not really helping the poorest of the poor, those people who do not have any assets right now. What you are doing is expanding the number of people who can come in. But those people with higher assets would tend probably to have more income and lower benefit levels. They are not the people who participate in great numbers in any event.

Acting Chairman **Downey**. I am almost tempted to laugh, higher assets, what, that they have are an extra couple of pieces of furniture or a car that may actually work. We are not talking about people with means here, are we?

Mr. **Carozza**. Mr. Downey, the SSI program excludes almost all assets that persons would need to conduct their daily lives. We totally exclude the value of the home. We exclude the value of personal furnishings, household furnishings, personal effects like clothes, and the value of term life insurance policies.

Acting Chairman **Downey**. You do not think the asset test should change in any way? It should not be expanded, made more generous?

Mr. **Carozza**. I do not think it would particularly help this problem. No, sir.

Acting Chairman **Downey**. Did you support the increase last time?

Mr. **Carozza**. I was not with the administration.

Acting Chairman **Downey**. Let the record show, I do not think you did or the SSA did. I think we kind of rammed it down your throat.

Mr. **Pollack**. Mr. Chairman, the asset standard in nominal dollars was expanded over a 5-year period from $1,500 to $2,000. It went up $100 per year. In real dollars, of course, it shrunk and for almost a decade there was not even an increase in nominal dollars. So in terms of the purchasing value that a beneficiary had at the inception of the program with the assets, it has shrunk dramatically. It is now about 50 percent less than what it was. To the extent there has been an expansion, it has been purely in nominal dollars, not in real dollars.

Acting Chairman **Downey**. Mr. Stark wants me to ask you, Mr. Carozza, about whether SSA has plans to establish the demonstration project referred to in House Report 100–689, which would help eligible homeless persons to sign up for SSI and other benefits to which they are entitled. Do you have plans to do that?

Mr. CAROZZA. Let me address that. The Congress authorized those projects, but did not appropriate any funding for them. In fact, our appropriation was reduced below the level that the President requested. So we just do not have the money to implement those demonstrations.

Chairman ROYBAL. I think we may have a discrepancy here on that. Mr. Stark, in a letter to Commissioner Hardy, says that in the report accompanying the appropriations bill, research and demonstration projects authorized under the 1987 budget Reconciliation Act, Public Law 100-203, are mentioned as follows: The committee directs the Social Security Administration to provide, not to exceed $1 million, to establish projects to demonstrate special procedures to ensure that homeless and individuals are provided SSI and other benefits to which they are entitled. Does that mean anything when we direct you in a report to spend the money?

Mr. CAROZZA. Yes, sir. It certainly does, but at the same time that that language was added our appropriation was cut, so we have the dollar amount that is appropriated in the law and language in the report that is not in the law.

Acting Chairman DOWNEY. Notwithstanding the reduction, which is lamentable, would it not still be appropriate that in the appropriation that was provided a portion of this money be used for this purpose?

Mr. CAROZZA. We would have to take it away from other important projects.

Acting Chairman DOWNEY. I think that is what he is saying or at least what the committee was saying, that between important projects, this was one that the Congress feels was a priority. Mr. Matsui?

Mr. MATSUI. Thank you very much, Mr. Chairman. I would like to ask you, Mr. Carozza, given the fact that you apparently think that we do not need to increase SSI, could you explain to me how Ms. Brown-Bey can cut her expenses in a way that she will be able to come out even on a monthly basis? You undoubtedly heard her testimony.

Mr. CAROZZA. I think, Mr. Matsui, it would be very difficult for me to do that here without being able to look at what those expenses were and what her individual situation was.

Mr. MATSUI. She did list the amount that she takes in on a monthly basis and certainly SSI is a last resort for her. She is 97 years old. It is very difficult for her to find outside employment. And as Mr. Downey indicated, her marriage prospects are probably not as good as perhaps some other individual. She listed her expenditures, mainly basic necessities. Perhaps you can define how we can come up with a little money for her or a little savings for her so she breaks even.

Mr. CAROZZA. I do not think I would be able to do that at this time. I think I would need a lot more information, such as what her other assets were.

Mr. MATSUI. I do not think she is going out to movies or anything like that. Assuming that she only has those expenditures she enumerated, where would she come up with savings?

Mr. **Carozza**. I would have to take a very close look at that.

Mr. **Matsui**. Let me move to the outreach program which you are so proud of. In your written testimony and your oral testimony, you talked about AARP and how you cooperated with AARP. It sounds to me, reading your written testimony, that no expenditures are coming from SSA in terms of the outreach program; is that correct? Except perhaps some staff time?

Mr. **Carozza**. Staff compiling data, things like that——

Mr. **Matsui**. In your written testimony you talk about demonstration programs in Pittsburgh, El Paso, Oklahoma City in which the AARP is working in a very major way to try to get some more people aware of SSI. What about cities that do not have an active AARP; what is happening in those cities?

Mr. **Carozza**. I can comment on that. Over the past couple of months, I have gone to maybe 10 or a dozen cities or so, just to look at what kind of efforts we have in place for some of our vulnerable groups—the homeless, the mentally ill, and alcohol and drug abusers. We have Social Security district offices throughout the country and we do outreach efforts through them. In all of the communities I went to, there are active private groups that do similar kinds of things.

To go back a second to Mr. Stark's letter, I specifically asked the operators of homeless shelters and the advocates in these cities I went to, what they thought about our using money to sponsor that type of demonstration. They told me that we really did not need that kind of demonstration project, that there were already organizations out there who were doing that, and that they really did not need Social Security to try to take the lead in that.

Mr. **Matsui**. And so, you have made these trips around the country to 10 cities and you gather from that that we have an SSA outreach program?

Mr. **Carozza**. Yes, sir, we do. As I said before, we can do better.

Mr. **Matsui**. Let me ask you this. Statistically, on a year-to-year basis, from 1987 to 1988, tell me what the increase—name a city that you went through?

Mr. **Carozza**. Toledo, Ohio.

Mr. **Matsui**. What has been the increase in the number of participants of SSI in Toledo, Ohio, from 1986 to 1988; do you happen to know that number?

Mr. **Carozza**. I do not have that offhand. But I can supply it for you.

Mr. **Matsui**. Name another city you went to of the 10?

Mr. **Carozza**. Boston. Baltimore.

Mr. **Matsui**. Boston—statistically from 1986 to 1988, has there been an increase in SSI recipients; do you know the number?

Mr. **Carozza**. I do not have those numbers.

Mr. **Matsui**. Are you working on any statistics? Are you concerned about this enough where you are asking——

Mr. **Carozza**. Yes, sir. The Department is looking at that question.

Mr. **Matsui**. Why do you not have numbers on those things?

Mr. **Carozza**. If I had a little bit of time, I could give you some specific numbers like that. I just do not have them here in front of me. I could furnish those for the record.

Mr. MATSUI. And also now, you are talking about this video tape, you mentioned Mr. Shelton, I guess, in Tennessee. The video tape goes to the providers; is this correct—the agencies? The video tape you are talking about in terms of outreach?

Mr. CAROZZA. It would go to providers and advocates, groups like that.

Mr. MATSUI. Mr. Shelton, I assume understands all the requirements of SSI, so why give him a video tape?

Mr. CAROZZA. I think we are fortunate with Mr. Shelton, but in most organizations we find that because of turnover and things like that, there are always new people coming in who do need that kind of training.

Mr. MATSUI. I wish you would look at the Pentagon and how they recruit people to join the service and perhaps you might learn from that, and maybe that way you can take care of some of the potential beneficiaries of SSI.

Mr. Shelton, you have Donna Lefebvre with you; is this correct?

Mr. SHELTON. Ms. Lefebvre.

Mr. MATSUI. Mr. Chairman, with your indulgence, I would like to ask Ms. Lefebvre a question. She is an attorney with Legal Services of Tennessee, and I would just like to ask her two very brief questions.

Acting Chairman DOWNEY. Absolutely, go right ahead, Mr. Matsui.

Mr. MATSUI. Ms. Lefebvre, in terms of children with disabilities and the eligibility for children with disabilities for SSI, under the current law, at least as the administration interprets it, a manifestation of the disability must occur before a child becomes eligible, even if we know from genetics and other studies that the child, in fact, has a disability; is that correct?

Ms. LEFEBVRE. That is correct.

Mr. MATSUI. In terms of a recent court decision, the Third Circuit Court of Appeals in Philadelphia, they just indicated that the evaluation given by SSA on childhood disabilities is incorrect; is that right?

Ms. LEFEBVRE. That is also correct.

Mr. MATSUI. What did they come up with—what was their recommendation, the court's recommendation?

Ms. LEFEBVRE. The way that Social Security looks at child's disability now does not consider anything beyond whether that child's medical problem is on Social Security listing of medical impairments. Or whether, and we are not sure exactly what this means, whether that medical problem is equivalent to one on Social Security's list. The court was saying that this approach ignored several basic problems.

First of all, the list was never meant to be an exhaustive list of medical problems. So children with medical problems that are not on the list, cannot be adequately considered. Also that fails to give a child an individualized determination. You have children like the one that Mr. Shelton described, one of those is a little girl named Brittany Duncan whom I represent. Brittany's medical problem with the problems with her Trisomy III-P chromosome mean that she not only has mental retardation, but a host of very serious physical problems. And the way Social Security views her case, her problems taken individually do not meet her or equal one of the listings, so she is denied.

Mr. **Matsui**. As a result of that, the Philadelphia case basically said that the Social Security Administration was not interpreting the legislation correctly; is that right?

Ms. **Lefebvre**. That is right. The Social Security Administration was not interpreting the term comparable severity that is in the statute in the appropriate way.

Mr. **Matsui**. Right. One of the problems with that though, assuming that the court's position is correct, you would like to make sure that we make some legislative changes to correct the interpretation given by the Administration; is this correct?

Ms. **Lefebvre**. It is terribly important to disabled children that this statute be clarified. That the term comparable severity be spelled out so that the Secretary, so that Social Security does not narrow it to the point where it is meaningless for disabled children. It is absolutely essential that you clarify it so that children get individualized determinations. That it is not left to the Secretary's discretion to decide how children are or are not comparably disabled to an adult.

Mr. **Matsui**. And I guess a concern that we all have is that even though the Philadelphia court is correct, and its views are similar to yours, the problem is that its jurisdiction does not extend to other jurisdictions throughout the country, so it is a very limited decision in terms of the population it serves. And secondly, the Secretary might in the near future ask for certiorari and bring the case to the U.S. Supreme Court in which case, obviously the decision could be overturned and we are right back to the status quo; is this correct?

Ms. **Lefebvre**. There is no telling exactly who the Zebly case will cover. It is supposed to be, it may be a nationwide class of children. However, the circuits that have already ruled on the issue may be carved out. Social Security is attempting to carve out a case in which I represent nine children. There is no telling who it will or will not help at this point.

Mr. **Matsui**. So you would prefer to see a legislative solution to this particular problem?

Ms. **Lefebvre**. From my perspective as an individual who represents disabled children and who has worked with disabled people applying for SSI for 12 years, the only solution is a clarification of this statute. Because I see Social Security not taking this problem seriously. And it is terribly serious for disabled children and their families.

Mr. **Matsui**. Thank you. I just have one further question. I will try to make this one very brief. Disabled children, 3 and under, there is a unique problem because it is very difficult to test them for their disability because oftentimes they cannot respond in a way that children 5, 10 or 15 may be able to respond. In a bill that we have introduced, Congressman Downey and Congressman Roybal, and myself, and Congressman Miller, we create a presumption of eligibility if certain tests are met for severely disabled children under 3. You indicated that you might have some further suggestions on that; could you just state that for the record?

Ms. LEFEBVRE. The presumption for children under 3 years old is excellent because what I have learned from working with people like Mr. Shelton, and from reading the medical records of children, is that they can be diagnosed for genetic abnormalities at a very early age, but time is of the essence in their getting services and treatment.

So the presumption provision is incredibly important, but it has to have teeth. Again, you need to spell out how children need to be treated by Social Security, because otherwise I believe they will not be treated well. Specifically, there has to be an emphasis on the early determination of disability.

When a child's parent goes into the Social Security office and applies, if they are denied coverage under a presumption provision, that ought to be treated as an initial determination and it ought to be appealable. Something they can question. There should be specific requirements that tell Social Security how long they have to make the decision whether that child is or is not covered by the presumption provision, because disability determinations go on forever. When a parent now walks into a Social Security office, they are told 6 to 8 weeks before any initial determination on disability will be made. It is not adequate for kids with serious medical problems like the children that we are talking about.

Also, there should be an expedited appeal, an appeal that occurs very quickly, for kids that are being touched by chromosomal and other disorders, congenital disorders. And there should be given a deference to the treating physician's opinions in kid's cases. Most circuits require that Social Security give deference to treating physician's opinions regarding the medical conditions of children. But here it is particularly critical that that be done.

Mr. MATSUI. Thank you very much.

Acting Chairman DOWNEY. Mr. Carozza, do you want to address some of the concerns that have just been raised?

Mr. CAROZZA. I would like to address the last one.

Acting Chairman DOWNEY. Please do.

Mr. CAROZZA. I would hate for the committee to think that we do not care about the denials of children applying for disability. We are quite concerned about this.

What we are doing right now is we are studying a representative sample of all of the cases that have been denied. If the study shows that we need to take some action or some remedial training we will certainly initiate the appropriate kind of action.

Mr. MATSUI [presiding]. Mr. Carozza, when do you think the study will be completed?

Mr. CAROZZA. In the fall.

Mr. MATSUI. Can you move it up a little bit?

Mr. CAROZZA. We can try, but it takes a while to do those kinds of analyses.

Mr. MATSUI. Our reconciliation process will probably start around the late spring and if you can come up with a recommendation, let us say by early summer, then perhaps we can incorporate it in any legislation that we might want to move on SSI this year.

Mr. CAROZZA. I would be happy to look into seeing how quickly we could do that.

Mr. MATSUI. Thank you. At this time, I would like to call on Representative Johnson.

Ms. JOHNSON. Thank you very much, Mr. Chairman, and I thank the members of the panel for their testimony.

We certainly ought to be able to do something about the problem with infants and eligibility. Score requirements, and not being able to look at the child's medical problems as a whole I think are things that it should be possible to address in a concrete, specific way that would ease the eligibility determination for young children and put those services in place much earlier.

I do commend you, Mr. Carozza, on your outreach program. While it obviously is not all we need, the statistics do support that it reverses the pace of the decline for the elderly programs and actually expands the rate of growth in disabled and blind programs. Our own green book statistics do show that it had an effect.

Having spent a lot of time in agencies of the kind you describe, I think the video thing is important, and we do need to move. We just need to spread it much more broadly than we have, and get into some of the organizations like senior centers and schools even, and PTA's, so there is much greater knowledge of what is out there. But I appreciate your comments.

Thank you, Mr. Chairman. I hope we will be able to address some of the things as we go forward this term.

Mr. MATSUI. Thank you, Representative Johnson.

I believe Dr. Boggs wants to make a comment.

Ms. BOGGS. I just wanted to make two comments on what the other witnesses had said.

Number 1, I happen to have been looking recently at the medical listings for children and my recollection is that the item on congenital defects refers to TaySachs disease and Trisomy 18, both of which are essentially not compatible with extended life. So we have a focus on the adult equivalent of not expected to live for 12 months, a very sever standard.

I do think that it would be very easy for the physicians, the pediatric community, to identify specific chromosomal and other nonfatal congenital disorders that do typically lead to a severe disability in childhood. I very much support those people who feel that it is important to get the treatment to the children. It is a Medicaid eligibility issue, I think, in many instances.

The other thing I wanted to say was apropos of the Social Security's public information posture. I think that the publications of the Social Security Administration are exceptionally well done. They are well written. They are brief. They are targeted on whatever issue the individual wants. I am talking about the pamphlets that appear in the racks, but I am also talking about even something like the Social Security handbook which is quite easy to use once you get the hang of it.

On the other hand, I am literate. A great many people who need SSI are not literate. I very seldom see a mention of Social Security or SSI on TV, which I think is the main media of communication for most people who are not literate, as well as for many of us who are. So I do think that there is a need for what might be called a comprehensive media awareness in the agency.

I also might add, to their credit, that I feel I get good responses from my contacts with people, whether it is in Baltimore or in the district offices. I am sure that not everybody is perfect, but my guess is their record is much better than the IRS.

Mr. MATSUI. I would like to thank you, Dr. Boggs, for your comments. I think you are absolutely correct. The source of information for many of the people that would be eligible for SSI is television and undoubtedly the Defense Department has used that very well, but we have to do a little better at SSI.

I appreciate your comments in terms of the brochures and pamphlets, because they are well written. The question is whether they are distributed in an effective way. Frankly, we have had hearings on that issue in the past, and from what I have seen, they have not been effectively distributed in the past. Perhaps SSA could do a little better job on that.

I would like to take this opportunity to thank all of the witnesses that appeared today. Your testimony has been excellent and very helpful to all of us, and thank you.

The hearing is adjourned.

[Whereupon, at 2:48 p.m., the hearing was adjourned.]

[Submissions for the record follow:]

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February 27. 1989

Representative Thomas Downey
Acting Chairman
Subcommittee on Human Resources
Committee on Ways & Means
13317 Rayburn H.O.B.
Washington, DC 20515

✓Representative Edward Roybal
Chairman
House Select
Committee on Aging
House Annex 1 - R712
Washington, DC 20515

Re: Hearings on H.R. 866, 867 and 868

Dear Congressmen Downey and Roybal:

For the above hearings, we wish to submit for the record on behalf of our clients and at your staff request, the enclosed listing of case examples from across the country of poor, disabled children who have been denied SSI children's disability benefits in the past. These children's cases, demonstrating the failure of SSA's restrictive, listings only evaluation policy for determining eligibility of child claimants, show the need for these bills' passage, especially of H.R.868, which would provide for a fairer and more realistic evaluation of the functional effects of a child's impairments.

Although we believe that the current SSI law's "comparable severity" standard requires such an analysis, as the decision we won in Zebley v. Bowen, 855 F.2d 67 (3d Cir. 1988) establishes, the government's continuing refusal to abide by the Zebley holding warrants prompt passage of the above legislation.

Sincerely yours,

Jonathan M Stein

JONATHAN STEIN
General Counsel

JS/sd

cc: Rep. George Miller
Rep. Robert Matsui

Enclosures

SUMMARIES OF SOCIAL SECURITY ADMINISTRATION DECISIONS DENYING SSI BENEFITS TO CHILD CLAIMANTS

Pennsylvania cases:

Dean O. -- spina bifida, Epstein-Barr virus, chronic diarrhea

Dean was denied benefits by an ALJ when he was two years old. He suffers from breathing problems, spina bifida, conjunctivitis, learning problems, anemia, and hyperactivity. His mother reports that he is destructive and occasionally bites himself. He has been hospitalized several times for dehydration with vomiting and diarrhea. He has been diagnosed as having Epstein-Barr virus; his chronic diarrhea (as diagnosed at Johns Hopkins Hospital) is listed as a symptom.

Weekly developmental therapy was prescribed when Dean was evaluated at age 26 months as having gross motor skills of 19 months, fine motor skills of 18 months, and cognitive and language skills of 17 months. He is in the 25th percentile for weight for his age and the 10th percentile for length, as noted by the ALJ. WIC has placed Dean in the high nutritional risk category. In his most recently listed evaluation, he was listed as having a 7 month delay in cognitive skills and an expressive language delay of 15 months, making him "significantly delayed."

Despite these impairments, the ALJ rejected Dean's attorney's argument that Dean's functional nonpsychotic disorder met listing 112.04 of the children's disability regulations (mental and emotional disorders). The ALJ stated that "while the child does have some physical problems and some slowness in mental and motor delay, he does not have an impairment or combination of impairments either listed in or medically equal to one listed . . . ."

Henry R. -- mental retardation, developmental disability

Henry was denied benefits by an ALJ when he was ten years old. In his Social Security consultative psychological exam, Henry tested as having a verbal IQ of 49, a performance IQ of 68, and a full scale IQ of 54. Although these scores alone satisfy child listing 112.05(B), the ALJ discounted the scores because the administering doctor diagnosed Henry as "only" mildly retarded. However, even in addition to these scores, Henry tests three years below his chronological age on Developmental Test of Visual-Motor Integration and two years below in Visual Aural Digit Span Test. These results indicate perceptual dysfunction that should itself constitute organic mental disorder under listing 112.05(c). Henry is maintained on Ritalin because of his hyperactivity, lack of concentration, and behavioral problems. Although he must continue to undergo behavior therapy, the ALJ determined that he did not specifically meet a listing and was therefore not disabled.

Richard D. -- chronic asthma, respiratory tract infections

Richard was denied benefits by an ALJ when he was six years old, and the denial was upheld by the Appeals Council. Henry's asthma required 17 emergency room visits and six periods of hospitalization during the approximately two year period from November 1984 to January 1987. He missed 67 days during his 8 month pre-school program and 21 out of 103 days of kindergarten. He uses a breathing machine 4 times a day for at least one hour at a time, and is presently taking Slobid, Alupent, and Prednisone. Henry is also plagued by complications by respiratory tract infections. Despite these clear functional impairments, the ALJ determined that Richard's condition did not meet the recent, recurrent, and intense requirements for the bronchial asthma listing (103.03).

Jason E. -- muscular dystrophy

Jason was denied benefits by an ALJ when he was five years old. His denial was eventually overturned four years later by a federal district court in 1988. According to his attorney, if Jason had been awarded benefits earlier, "his condition perhaps would not have deteriorated as rapidly." For example, occupational therapy had been recommended three times per week, but Jason's family could not afford the treatment.

At the time of denial, Jason had difficulty walking and was unable to grasp and control a pencil. He needed help dressing and eating and required speech therapy since his mouth and vocal cords were affected by his degenerative disease. He often crawled at school because he became exhausted by the end of the day. Despite the medical advisor's testimony that muscular dystrophy "results in motor dysfunction grossly affecting both his upper and lower extremities, which definitely interferes with age-appropriate daily activities," Jason was initially denied benefits because he did not meet listing 111.06 for motor dysfunction. He has now experienced hypertrophy of calf muscles and "disruption of fine and gross movements and gait and station," and is confined to a wheelchair or carried by his parents.

Yolanda D. -- mental retardation, developmental disability

Yolanda was denied benefits when she was 11 years old. Her latest IQ test revealed a verbal IQ of 72, performance IQ of 84, and full scale IQ of 76. She is enrolled in a special education/educable mentally retarded class, and, according to her teacher, requires more personal attention and has lower achievement than any other student in the class. Yolanda's personal hygiene is well below average, and she "wets and soils her clothes at home and at school." Both her visual motor integration and language development and communications skills are extremely delayed.
Although the ALJ acknowledged that "because of her mental ability,

she would be limited to simple, repetitive tasks," he found that she did not meet listing 112.05 for mental impairments.

Harvey M. -- Gran mal epilepsy

Harvey was denied benefits by an ALJ when he was eight years old. He suffers from gran mal epilepsy with a history of psychomotor seizures, during which he either experiences generalized shaking or sits and stares. Harvey also has a history of conduct disorder and his "fine motor control and the auditory and visual memory retention [are] poor and he needs special assistance to acquire the necessary skills to function." An IQ test administered in June, 1987 revealed a verbal IQ of 70, performance IQ of 91, and full scale IQ of 79. The evaluation also showed "limited abstract thinking," and "[h]is coordination dexterity and manipulation skills were below a first grade" level. The ALJ held that Harvey's condition did not meet listing 111.02 because his condition could be treated.

Joseph L. -- organic brain syndrome

Joseph was denied benefits at age ten. He suffers from organic brain syndrome manifested by psychiatric and neurological impairments, the most pronounced of which are an adjustment disorder with mixed emotional and behavioral disturbances and hyperkinesis. In his early childhood, Joseph would go to sleep at 2 a.m., awaken at 6 a.m., constantly climb onto things, and run up and down steps. He failed first grade three times, could not adapt to special education classes, and required home-bound instructions. He was only awarded benefits by being a plaintiff in the Zebley litigation in the U.S. District Court in Philadelphia, Pennsylvania.

Northeastern cases:

Valerie H. -- cystic fibrosis, diabetes, asthma, scoliosis
Vermont

Valerie was denied benefits when she was sixteen years old. She has had cystic fibrosis since birth and is hospitalized for a week every two or three months for pneumonia resulting from her disease. In 1986, her treating physician reported that her cystic fibrosis would lead to a shortened life expectancy. Valerie also suffers from diabetes, asthma controlled by medication, and scoliosis. She takes forty pills per day plus insulin and use of an inhaler. She has asthma attacks approximately once a week.

The ALJ found that Valerie did not meet the specific requirements for the listings for cystic fibrosis, asthma, diabetes, or scoliosis, and refused to consider her impairments in combination. Despite a doctor's opinion that Valerie was disabled, the judge noted that "[i]n the absence of pulmonary function test results which meet the specific criteria of the section dealing with cystic fibrosis (section 103.03), no finding of disability can be made."

M.B. -- severe personality disorder
Vermont

M.B. was initially denied benefits as a child, but at a rehearing at age 22 was awarded benefits as an adult based on the same medical evidence but applying the adult test. M.B. was diagnosed as a child with "adjustment disorder with mixed disturbance of emotions and conduct and a mixed developmental disorder." She was removed from her natural parents at age two because of physical abuse. She was then removed from adoptive parents and a subsequent foster home for suspected sexual abuse, and was moved approximately 20 times through successive foster home placements. A child psychiatric social worker who conducted regular therapy determined that M. "had not developed a level of emotional maturity sufficient to function without support."

M. has attempted suicide at least three times (at least once requiring hospitalization), has threatened teachers with physical violence, and was arrested and held in prison for assaulting a police officer. Her emotional disorder causes her to become angry and frustrated very quickly, and she is unable to control her mood. Her school administrator stated that her "emotional instability kept her from doing functional school work."

Despite the ALJ's finding that "the claimant has a medically determinable mental impairment," he found she could be considered disabled only under the residual functional capacity test available only to adult claimants, and not under the specific listing for mental impairment applicable to children under age 18. He acknowledged that her condition was essentially the same before and after age 18, but awarded benefits only as of the date of her eighteenth birthday. After being denied on multiple levels of rehearing, M.B. was finally awarded benefits by the Appeals Council retroactive to the date of her initial application.

W.B. -- seizures, mental retardation
Vermont

W. was diagnosed at age two with severe behavior and seizure disorder. He has been hospitalized repeatedly, for example six times during 1982 for seizures, Dilantin toxicity, gastroenteritis, vomiting, and dehydration. W. has been hospitalized several times for uncontrolled seizures, and a doctor testified that they are still not controlled.

Intelligence tests administered in 1982 revealed a verbal IQ of 52 and a performance IQ of 60. In 1981, a psychiatrist's evaluation was that W. was an "extremely handicapped individual who needed continuing support and further psychiatric treatment . . . [who was] totally dependent on his parents, suffered from epilepsy and had a mild degree of mental retardation and behavioral problems in the form of expletive outbursts." His father testified that W.B. functioned as a five or six year old child.

W. originally applied for benefits in 1980, and after repeated denials and rehearings, was finally awarded benefits in 1986. The award appears to be based solely on the results of the 1982 IQ test, under listing 112.05(B) (IQ of 59 or less), rather than on the combination of medical and functional impairments that also existed before that date.

Midwest and Southwest cases:

Blake D. -- asthma, gross obesity, hypertension

Texas

Blake was denied benefits when he was eleven years old. At that time he weighed 241 pounds, was 64 1/2 inches tall, and had recorded blood pressure of 130/110 (which had reached a high of 190/110). Blake has been hospitalized several times for asthma and has been diagnosed with hypertensive encapalopathy, vertigo, severe headaches, asthmatic bronchitis, and an endocrine disorder. He has difficulty breathing and has daily nosebleeds; he was once hospitalized for a weeklong nosebleed. He is too young to be prescribed medication for his hypertension. Blake has had headaches so severe as to cause temporary loss of vision.

The ALJ found that Blake did not meet the listing requirement for either asthma, obesity, or hypertension. The listing for children's obesity did not contemplate a child's weighing as much as Blake did at the time of decision, and the ALJ refused to evaluate Blake by adjusting the adult weight listing to account for the expected continued weight gain of children. Blake has filed an appeal for benefits in federal district court.

Jennifer C. -- anorectal atresia, bladder dysfunction

Iowa

Jennifer was denied benefits at age five. As an infant, Jennifer underwent surgery performing a colostomy, relocation of anus, and then closing of the colostomy. She now suffers from chronic constipation that will require additional surgery. She is unable to sense when her bladder is full and constantly wets herself both at home and during school. Her bladder dysfunction is accompanied by repeated urinary tract infections. A doctor testified that Jennifer's "constant constipation affected her personality significantly." In addition, Jennifer has an eye muscle deficiency resulting in a lack of peripheral vision diagnosed as Duane's Syndrome.

The ALJ held that no single one of Jennifer's disabilities met a required listing. The judge specifically rejected an evaluation of "functional impairment from her multiple disabilities" on the grounds that such an evaluation constituted a residual functional capacity determination not permitted under the child disability regulations.

Takesha -- spina bifida, paralysis, club foot, hip disorder
Illinois

Takesha was denied benefits initially and on reconsideration. She is now eight months old. Takesha suffers from spina bifida, characterized by a sac formed around her fifth vertebrae that has caused damage to her nerve roots. As a result, she is permanently paralyzed from the knees down and will require braces or some assistance. She also suffers from non-compensated hydrocephalus, where the accumulation of fluid in her brain cannot be corrected by use of a shunt. Takesha was hospitalized for most of the month of January. In addition, she has a club foot a hip disorder resulting from her other medical impairments.

In February, 1989, an ALJ reversed the earlier administrative decisions and awarded benefits to Takesha based on her impairment as medically equivalent to child disability listing 111.08 for spina bifida.

Southern cases:

Kendrick B. -- cystic fibrosis
Mississippi

At the age of three months, Kendrick was diagnosed with severe anemia, growth retardation, and pancreatic cystic fibrosis. Although he received SSI benefits for two years, the benefits were discontinued when an ALJ found that he did not meet the forced expiratory volume test required by the pulmonary disorder listing. Despite Kendrick's mother's claim that she could "not afford to continue purchasing the medication" necessary to maintain his condition, the Fifth Circuit Court of Appeals affirmed the denial of benefits for failure to meet the listings. Burnside v. Bowen, 845 F.2d 587 (5th Cir. 1988).

Brittany D. -- partial trisomy 3 p chromosome
Tennessee

Brittany was initially denied benefits when she was less than one year old, and the denial was upheld by an ALJ when she was approximately 19 months old. At eight months old, she was diagnosed as mentally retarded with a developmental age equivalent of 5 1/2 months. In the same evaluation, the examining medical consultant diagnosed "chromosomal aberration associated with craniofacial dymorphism, congenital heart defects and mental retardation." Brittany suffers from a large umbilical hernia, repeated seizures and fevers, and recurrent pneumonia. Her developmental age equivalents under the Bayley Scales of Infant Development were all delayed more than one half of her chronological age.

Despite Brittany's tested severe developmental delay, the Secretary found that she did not meet listing 112.05(B) for mental retardation. The listing recognizes only standardized IQ testing and does not consider infants that may be too young to be tested.

Stephanie M. -- brain damage, apnea, immunodeficiency problem

Tennessee

Stephanie was born prematurely in April, 1988. She suffers from a seizure disorder, immune deficiencies, and had an abnormal EEG in August. Stephanie cannot sit up, control her head, or roll over. Stephanie was denied benefits both on initial application and rehearing, although no specific listing was noted as not being met. As suggested by her attorney, she is a good example of a child with multiple disorders, none of which meets one specific child disability listing but which cannot be considered on their combined effect.

Christina -- cerebral palsy, severe developmental delay

Tennessee

Christina is now almost two years old. She has been denied benefits both on initial determination and on reconsideration. She has been diagnosed with cerebral palsy and suffers from hydrocephalus ("water on the brain") requiring two shunts to drain fluid. Christina is not able to sit up, crawl, or walk without assistance and is severely developmentally delayed. In addition, she has strabismus (crossed eyes) for which she will require surgery. Despite her impairments, the Social Security Administration has determined that she does not meet the listings for cerebral palsy.

R.S. -- fused spine, developmental delay

Tennessee

R.S. is two years old and has been denied benefits both by the Social Security Administration and on appeal to an ALJ. His cervical spine is completely fused. As a result, R.S. has no motion in his neck and severely limited use of his arms. According to his attorney, he is at constant risk that a wrong movement could snap a piece of his spine. In addition, R.S. is developmentally delayed and resides in an in-home psychological program.

The ALJ found that R.S.'s impairment did not meet the musculo-skeletal listing and did not consider his developmental delay.

James Derik -- chronic liver disease, allergy to all food

Alabama

James Derik was a 10 month old child with Alpha I Antitrypsin deficiency, a rare chronic liver disease. Derik is essentially confined to his home, leaving only for doctor visits. He has been hospitalized four times since birth. Uncontroverted medical evidence established that his condition is life long, precluding a normal childhood and adult life. He arms, legs and feet swell up causing pain. He has allergic reactions to any kind of food, and he has a limited ability to eat. He runs a fever three or four nights a week. Derik requires constant attention and when he experiences swelling, must be held all night. In addition to his liver disease, Derik has a history of associated mild conjunctivitis and hepatomegaly, left inguinal hernia, gastroenteritis, and developmental delay.

Derik's application for SSI was denied five times, including at the federal district and circuit court levels, on the grounds that his condition did not meet the listings. Wilkinson v. Bowen, No. 86-7855 (11th Cir. July 15, 1987).

West Coast cases:

Russell C. -- lead poisoning

Russell was a ten year old boy who suffers from the residual effects of being lead burdened as a young child. The damage from being lead burdened manifests itself in various ways: in poor auditory memory and sequencing, in significant delays and deficits in fine and gross motor areas, and in visual-perceptual motor integration at the level one would expect of a child at age 5 1/2 to 6 years. He scored low on tests measuring his level of social adaptiveness, he has behavioral problems, and he cannot write his last name.

Tiffany M. -- Down's syndrome, congestive heart failure

Tiffany was a three year old girl with congestive heart failure in addition to Down's syndrome. At the age of 15 months, Tiffany was found to have a developmental delay of over fifty percent. The symptoms of her severe heart and pulmonary conditions include difficulty breathing, decreased physical ability, repeated pneumonia and decreased ability to withstand infection. She has required extensive medical treatment for her problems. According to her doctors, her growth early in life could have been promoted only by the "expertise" and "tenacity" of her foster mother.

Despite her severe medical impairments, Tiffany was denied SSI benefits initially and upon reconsideration. Her claim was finally granted over one year after her application was filed. The notice of reconsideration dated April 15, 1985 (over 14 months after Tiffany was born) states that although Tiffany has Down's syndrome,

> It ~~is~~ impossible to fully assess any limitation this condition might have on her mental capability due to her young age. Therefore, the severity of your child's condition does not meet the severity of the special requirements for Disabled Child's benefits.

Angela L. -- respiratory distress syndrome, profound central nervous deficit

Angela L. was a 10 month old girl who suffers from respiratory distress syndrome and a very profound central nervous deficit. Due to these impairments, Angela has the developmental status of a newborn infant. She has no functional use of any extremity and must be fed by a gastrostomy (feeding) tube. She also requires constant supervision to ensure that she keeps breathing. She needs percussion and pulmonary hygiene on a routine daily basis to clear secretions from her lungs.

Angela's twin sister, Amy was granted SSI benefits upon her initial application. A comparison of the medical records of Amy with those of Angela demonstrate that the infants had very similar functional limitations, but that there were some minor differences in their test results. Apparently, Amy's test results did meet a listing, while Angela's did not. According to their social worker, both twins have a similar degree of respiratory distress.

Courtney M. -- Down's syndrome, choanal stenosis

Courtney was a 16 month old girl with Down's syndrome. She also suffers from choanal stenosis, a chronic blockage and scarring of the nasal passages due to chemical burns which were caused by a mistake in her treatment at the hospital. She has had multiple health problems requiring frequent hospitalizations since her birth. She receives most of her nourishment through a feeding tube, and she requires close supervision by a trained person to monitor her feeding and to keep her nasal passage open. Courtney now sees a total of six physicians to monitor and treat her multiple health needs. According to Courtney's social worker, the family's finances are strained due to extensive medical treatment, and Courtney's health problems have caused and continue to cause great anxiety.

Despite her severe disabilities, Courtney twice has been found not to be disabled: once upon her initial application for SSI and once upon appeal. The initial and reconsideration decisions both reflect that extensive evidence of Courtney's condition was provided to the Social Security Administration, and that Courtney nonetheless was found not to meet the "special requirements for SSI benefits for a disabled child."

Katrina P. -- cystic hygroma, hemangioma

Katrina was 12 1/2 months old. When her SSI application was filed, she had already had a tracheostomy (an opening in the neck for breathing and through which mucous must be regularly suctioned) and a gastrostomy (tube into stomach for food and liquids). The hygroma/hemangioma is a large tumor which obstructs breathing and eating passages. It is expected to continue growing for several years.

Katrina's mother is unable to continue working because of

Katrina's need for constant skilled supervision. Due to lack of funds, Katrina and her mother live in a cockroach infested apartment. Nurses have observed cockroaches crawling into Katrina's suctioning equipment. Katrina's mother is very depressed and suffers from lack of sleep because she must constantly listen to be sure Katrina is still breathing.

Yukiea B. -- hydrocephalus, myelomeningocele (spina bifida)

Yukiea was a six month old child with a congenital birth defect consisting of hydrocephalus and myelomeningocele (an incompletely fused spine) or spina bifida. A surgical tube has been placed in her head to drain off excess water as it collects on the brain. She is unable to crawl or use both legs due to partial leg paralysis. Her partial paralysis and loss of bladder and bowel control are expected to be permanent. She will require intensive and ongoing medical care for the rest of her life, according to her doctors. Yukiea's mother was forced to quit working to take care of her.

Jeffrey -- Tourette's Syndrome

Jeffrey was a thirteen year old with Tourette's Syndrome, a severe neurological disorder. Jeffrey's syndrome causes persistent disorganization of motor functions, including all four extremities, on a regular basis. Jeffrey also suffers from severe and frequent facial tics, nervous jerks, and uncontrollable grunts and barking caused by his condition. Jeffrey's ability to participate in normal activities is severely restricted. He has extreme difficulty concentrating and engaging in normal play activity.

February 25, 1989

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DECEMber 21, 1985

Ailing baby's family seeks assistance, and answers

By Anemona Hartocollis
Inquirer Staff Writer

His sister calls him the "Smurf baby," because he gags and turns blue every time he tries to cry.

When Jason Sass was born 10 months ago, his spine protruded through a hole in his back and he had water on the brain. He is paralyzed from the waist down, cannot drink liquids and has extreme difficulty swallowing any food at all.

The Social Security Administration says he is not sufficiently disabled for his family to receive benefits.

Jason requires constant care, and his mother, Anita, stays home in Warminster, Bucks County, to give it to him. After Jason was born in March, Anita Sass, 27, had to leave her job at a supermarket, where she earned $11 an hour wrapping meat.

The baby's father, Robert, 26, is a third-year medical student at the Philadelphia College of Osteopathic Medicine. He has borrowed $60,000 for his education, and he is reluctant to abandon it in midstream. But when Anita Sass left her job, the family lost its only source of income.

Anita and Robert Sass thought they would find a safety net in Supplemental Security Income, a federal welfare program for the disabled. They believed that they were sure to qualify for the program, based on their low income and Jason's medical problems.

They were wrong. SSI officials have rejected the application twice, on the ground that Jason was not sufficiently disabled. The family has applied a third time. Meanwhile, the Sasses are falling deeper into poverty.

Anita Sass believes the rejection was "crazy," and her doctor and even some SSI officials say they cannot understand it. John Seager, an aide to Rep. Peter Kostmayer (D., Pa.), the

(See BENEFITS on 4-B)

(Continuation of
this article was
not supplied.)

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Benefits fight

New rules sought for deciding disabled children's eligibility

By Anemona Hartocollis
Inquirer Staff Writer

Brian Zebley was born with brain damage. At age 4, he functioned at the mental level of a 2-year-old, walked with a limp, slurred his words, drooled heavily and was not toilet-trained.

The Social Security Administration acknowledged all of those conditions.

But following a review of Brian's case in 1983, the agency cut off the benefits he had been receiving for two years, saying he was not sufficiently disabled to qualify for the program, called Supplemental Security Income (SSI).

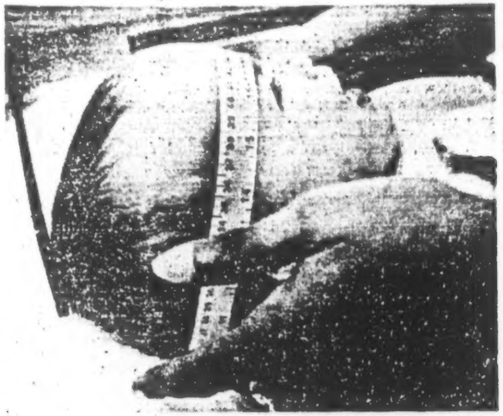
Brian, who lives in Upland, Delaware County, is not alone, say medical experts and advocates for the disabled. According to a lawsuit filed in Brian Zebley's behalf in 1983, thousands of children under the age of 18 are denied SSI benefits every year under "arbitrary" and "capricious" medical standards.

The suit, filed in U.S. District Court in Philadelphia against the Social Security Administration and still pending, demands that the agency create a new SSI standard that evaluates the ability of children to function, much as the adult standard evaluates adults' ability to work.

The lawsuit states that children are subject to more rigid rules than adults and that this double standard violates the intention of Congress in 1972 when it enacted SSI, a welfare program for the mentally and physically handicapped. The rules for children have not changed since then, say advocates for the disabled, even though knowledge about childhood disabilities has grown much more sophisticated.

In the court papers, agency lawyers contend that the rules are a reasonable interpretation of a policy set down by Congress and that it is up to Congress to change that policy. They say the Zebley case raises issues that were already decided in the Social Security Administration's favor, in two decisions, in 1982 and 1984, in circuit courts in Georgia and Massachusetts.

Charlotte Hardnett, the SSI lawyer in the case, declined comment, saying it was against federal policy to discuss pending litigation. But Jim Brown, press officer for Social Security, said the standards for children were "fair and equitable."



The Philadelphia Inquirer / GERALD S. WILLIAMS

Jason Sass, born with an enlarged head, was rejected for benefits

Attorneys associated with the Zebley case said, however, that partly as a result of the lawsuit the government had agreed to form a committee to review the SSI standards for children.

Congress ordered a review of SSI policy for mentally disabled adults two years ago, and the result was a new standard, implemented in August, that more closely linked disability with the inability to work.

After the Reagan administration cut 500,000 children and adults from SSI and Social Security disability, Congress passed legislation in 1984 that prohibited such terminations unless the recipient had shown clear improvement.

But there has been no congressional mandate to look specifically at the physical or mental standards used to evaluate children.

In a case last week, the Social Security Administration agreed to reconsider granting benefits to Jason Sass,

(See LAWSUIT on 5-B)

New rules sought in deciding on benefits for young

LAWSUIT, from 1-B

a 10-month-old infant from Bucks County, whose case strongly resembles that of Brian Zebley.

Jason has a gag reflex that hampers his eating and breathing, spina bifida, paralyzed legs and other birth defects. His parents applied for benefits twice and were rejected on the grounds that Jason was not sufficiently disabled and that he was too young to be accurately evaluated.

SSI officials in Wilkes-Barre agreed to reconsider his application under pressure from U.S. Rep. Peter Kostmayer (D., Pa.). Kostmayer asked for a "presumptive judgment," which would award benefits temporarily, until the child could be further evaluated.

The standards for children repeatedly have been challenged in court in individual cases. But *Zebley vs. Heckler* is the only pending class-action lawsuit seeking to force a sweeping change in the standards applied to disabled children, the attorneys said.

Advocates say that because of the narrow interpretation imposed by the Social Security Administration, the program now serves but a fraction of the needy children who are entitled to assistance.

"We don't know how many more children could qualify if the disability standards were more reasonable," said Joseph Manes, senior policy analyst for the Mental Health Law Project in Washington.

Cases such as those of Jason Sass and Brian Zebley are "just the tip of the iceberg," said Jonathan Stein, director of Community Legal Services in Philadelphia, which filed the Zebley lawsuit with Mark Kaufman, a lawyer for Delaware County Legal Assistance.

More than 230,000 children nationwide receive SSI, including more than 12,000 in Pennsylvania. Each year, the agency rejects more than 23,000 children on medical grounds.

Applicants first are screened for income and assets, then for physical and mental disabilities. The program provides a monthly cash payment, and it automatically qualifies the child for Medicaid. In many cases, officials said, the Medicaid, which pays for hospital and doctor bills, is more important than the cash, which amounts to a maximum of $325 a month and will go up to $336 in January.

Brian Zebley, like most children rejected on medical grounds, was disqualified because his disorders did not precisely match those on the "Listings of Impairments," a catalogue of eligible ailments that is the main target of the lawsuit.

If children fail to match the list, they must have impairments that are of "comparable severity" to those that disable an adult.

The lawsuit contends that since impairments of adults and children are not comparable, the agency has been quick to disqualify children. And advocates say that in practice, each ailment is considered separately, so that children with multiple ailments — which are more severe in combination than alone — are disqualified "as a general rule."

Thousands of adults who fail the listings test are still declared disabled under the law if they are not able "to engage in substantial gainful employment." But since children are not expected to work, they can't qualify under this provision.

The lawsuit says that the listings promote "administrative convenience and efficiency" by providing a shorthand way to evaluate children.

"There has never been any specific process for children," Stein said. "You get caught up in the difficulty of comparing children and adults. You have to make a leap of judgment. It's very discretionary. If you get the word from Washington to keep awards down, to be as harsh as possible, then you have room for a large number of denials."

Zebley vs. Heckler wants to force the Social Security Administration to develop a standard that would go beyond the listings, by measuring the ability of children to function at home or at school in the same way that the adult standards weigh the ability to work.

Children under the age of 2, Manes said, routinely fall through the cracks because they are too young to be evaluated under the criteria of the listings. For instance, the listings define mental retardation as an IQ of 59 or below. Thus a child who could not be tested for IQ would not qualify for benefits, Manes said.

Although filed two years ago, the lawsuit is still waiting to go to trial before Judge John Fullam. Government attorneys filed a motion to dismiss the case in March, based on the Georgia and Massachusetts rulings, and Fullam has not yet ruled on that motion.

Meanwhile, the Mental Health Law Project has been urging the Social Security Administration to review the disability standards for children, and a "working committee," made up of federal officials and independent experts, was established in June. Leonard Rubenstein, legal director of the Mental Health Law Project, credits the Zebley case with goading Social Security into reviewing the standards.

"Social Security, in a new spirit of trying to conform its rules with medical knowledge and the realities of what disability means, agreed to follow up the adult mental impairment review with new rules for children," Rubenstein said.

But Manes predicted that changing the regulations would be a slow process. "Historically, the government is very cautious about changing standards," he said. "They want to explore all the unanticipated consequences. It's a long process, and this infant will be bar mitzvahed before it's done."

TESTIMONY OF ANDREW KOSKI
PUBLIC POLICY COORDINATOR
INSTITUTE ON LAW AND RIGHTS OF OLDER ADULTS
BROOKDALE CENTER ON AGING OF HUNTER COLLEGE

Good afternoon, members of Congress. My name is Andrew Koski. I am Public Policy Coordinator of the Institute on Law and Rights of Older Adults, part of the Brookdale Center on Aging of Hunter College. The Law Institute researches the laws and regulations pertaining to entitlements such as Medicare, Medicaid, and Supplemental Security Income (S.S.I.), and provides publications that explain these programs for agencies serving the elderly. Also, we conduct seminars on public benefits for both service providers and for seniors and we represent recipients who have faced denials, terminations or reductions in benefits (including S.S.I.).

As a professional working in the aging field, I want to express my gratitude to the House Select Committee on Aging and the Ways and Means Subcommittee on Human Resources for holding today's joint hearing. Recently there have been many reports claiming that the elderly are financially secure and no longer require governmental assistance. However, these "studies" ignore the fact that some groups, particularly minorities and single women, include many elderly people whose annual income falls below the poverty level and others whose income only barely surpasses that level. For example, 34% of elderly Black people and 27% of elderly Hispanic people had income below the poverty level in 1987. (U.S. Dept. of Commerce, Bureau of the Census, 1987). Furthermore, 40% of all older women had incomes below 150% of the poverty level in 1986. (Commonwealth Fund Commission on Elderly People Living Alone, Medicare's Poor, Nov. 1987).

As S.S.I. is the only cash assistance program for poor elderly, visually impaired, and disabled individuals it is appropriate and timely to discuss how it can be changed to help this needy population.

The Supplemental Security Income program was established by Congress in 1972 to reduce poverty among the elderly, visually impaired and disabled. It provides a minimum income to meet the need for food, clothing and shelter. Unfortunately Federal SSI benefits bring single people up to only 73% of the poverty level and couples up to 82% of the poverty level. While about half of the states provide an SSI supplement, only five states contribute sufficient funds to bring recipients up to the poverty level.

Our experience has been that in New York -- where the state supplement is $86 per month, resulting in a total benefit of $454 -- people cannot survive on their monthly check. It is difficult to locate housing for less than $400 a month and if you add utility and food costs you can understand why recipients may run out of money before their next check arrives.

We have encouraged New York State to increase its contribution to S.S.I. and, in fact, New York has raised its supplement twice in the past four years. However those increases have been small and their value has been eroded by inflation. We believe both the Federal and State governments have a responsibility to help improve the lives of S.S.I. beneficiaries and urge you to consider legislation to raise the Federal portion of S.S.I. to at least the poverty level.

Another part of the S.S.I. program that warrants attention is the amount of liquid assets which recipients are allowed. The limits (individuals - $2,000, couples - $3,000) have not increased substantially since the inception of the program (in 1974 individuals were allowed $1,500 and couples were allowed $2,000) and need to be revised.
The low asset levels restrict the ability of recipients to rely upon their savings for economic support. In addition, people who have low income, but

who also have savings just above the the asset levels, are excluded from receiving S.S.I. We support a modest change to raise the resource limit to the level it would be if it had kept pace with inflation.

An inequity that needs to be addressed is the treatment of "in-kind assistance" received by S.S.I. recipients. In-kind assistance is defined as anything that is not cash and that can be used to meet the need for food, clothing or shelter. This includes rental payments and food purchases by family members and friends. If a daughter pays the rent for her mother who is on S.S.I., the Social Security Administration will count the value of such assistance and reduce the mother's S.S.I benefits by that value, up to a maximum monthly reduction of $142. This rule discourages families from helping their loved ones on S.S.I. and runs counter to government efforts to assist families and strengthen their bonds.

Related to the concept of in-kind assistance is the rule that if S.S.I. recipients live with someone else and receive both food and shelter assistance, they face a reduction of one-third ($142) in their Federal S.S.I. benefits. This penalizes families who choose to live with disabled children or their elders and to provide them with support.

The most favorable way to address this inequity is to disregard in-kind assistance as income. Currently the Social Security Administration does not count in-kind assistance given by a non-profit organization to a "needy" S.S.I. recipient. It is hard to justify dissimilar treatment of in-kind assistance by families or friends. If such a proposal is too costly, then a helpful reform would be to decrease the reduction of Federal S.S.I. benefits from one-third to one-sixth so that the maximum reduction would be $81 each month.

In summary, we believe that S.S.I. benefit levels should be raised to at least the poverty level, that the asset levels should be increased and that the rules concerning in-kind assistance need to be revised.

The Law Institute's recommendations are based upon ten years of experience in working with poor elderly people. We have encountered S.S.I. recipients who have to live in substandard housing because they cannot afford an apartment. Some have to rent a room in another person's apartment because housing costs exceed the monthly S.S.I. benefit, while others have to remain in deteriorated accommodations in unsafe neighborhoods.

I have visited S.S.I. recipients who use their home-delivered meal for lunch and dinner because they cannot afford to purchase enough food. While these people struggle to survive on S.S.I., many others cannot locate reasonably priced housing, and therefore become homeless. Without housing, their social support system disappears and their mental condition deteriorates. Some enter hospitals, require costly care and are discharged back to the community. The less fortunate die on the streets.

We are aware of the budget deficit, but the plight of poor elderly, visually impaired and disabled individuals requires government action. If the government fails to help those impoverished people who cannot help themselves, who will?

Thank you for the opportunity to present our views.

Statement
of
Alan V. Reuther
Associate General Counsel
International Union, UAW

Mr. Chairman, my name is Alan Reuther. I am an Associate General Counsel for the International Union, UAW. This statement is submitted on behalf of some 1.5 million active and retired members of the UAW and their families.

The UAW appreciates the opportunity to present our views on the Supplemental Security Income (SSI) program. We commend the Select Committee on Aging and the Subcommittee on Human Resources of the Ways and Means Committee for holding a joint hearing on the SSI program, which is so important to millions of lower income elderly, blind, and disabled persons.

The SSI program was enacted in 1972 in an effort to place an economic floor under the nation's aged, blind, and disabled. It replaced a patchwork of state programs which contained widely varying eligibility requirements and benefit levels. The intent of the SSI program was to supplement the income of poor persons whose work experience and/or circumstances did not qualify them for coverage under Social Security, or whose benefits under Social Security were inadequate for subsistence.

The SSI program provides a nationally uniform guaranteed minimum income for the aged, blind, and disabled. SSI currently pays benefits to about 4.4 million people. About one-third or 1.45 million of them are elderly.

Despite the enactment of SSI, we still have not realized the goal of providing all elderly, blind and disabled citizens with a minimally adequate income. SSI has a number of major deficiencies which keep millions of these persons in poverty.

First, the federal SSI benefit standard falls substantially below the poverty line. In 1988, the maximum federal SSI benefit for an elderly individual was just $354 per month ($4,248 annually) — or approximately 75 percent of the projected poverty level of $5,649. For elderly couples, the maximum federal benefit standard was $532 per month ($6,384 annually), or 90 percent of the projected poverty level of $7,126.[1]

Although SSI's funding structure permits states to supplement federal benefits, the median state supplement is only $36 per month for an elderly individual. Only four states (Alaska, California, Massachusetts and Connecticut) provide supplements to elderly individuals which bring their incomes up to the poverty level when added to the federal benefits.

Second, elderly persons cannot qualify for SSI benefits unless they have extremely limited "countable assets" — not more than $1,900 for an individual and $2,850 for a couple in 1988. It is important to note that this limit has not changed substantially since SSI was passed in 1972. In that time, inflation has eroded the value of the dollar by more than half, meaning that today the asset limit is effectively more harsh than in 1972.[2] Many poor elderly, blind and disabled individuals thus find themselves barred from participating in SSI because they have "too many" resources.

Third, SSI simply does not reach many of the people who do meet eligibility criteria. About half of the potentially eligible population does not participate, usually because of a lack of knowledge about the program. In a 1983 study, the Social Security Administration found that 45 percent of those who were eligible for SSI but not participating had no idea that SSI existed. Among elderly households with incomes below the poverty line, only 32 percent participated in the program.[3]

Congress tried to address this problem in 1983 by requiring the Social Security Administration to notify low income Social Security recipients that they might be eligible for SSI. However, this was only a one-time requirement, and the evidence suggests that the information did not circulate widely enough or that limited SSI benefits and administrative red tape discouraged large numbers of the elderly from applying for benefits.

Thus, the overall effect is very clear. SSI simply does not reach most of the elderly, blind, and disabled persons who are in need and even when it does, the level and scope of benefits provided are inadequate to meet beneficiaries' needs.

Representatives Matsui, Downey, Miller, and Roybal have recently introduced the proposed "SSI Benefit Improvements Amendments of 1989" (H.R. 866), which would address these major deficiencies in the SSI program by:

- raising the federal benefit standard in three steps until it equals the HHS poverty income guideline in 1992;
- raising the "countable asset" test to $4,200 for an individual and $6,300 for a couple (the levels which would have been reached had the 1974 levels kept pace with inflation); and

- o requiring the Social Security Administration to establish and conduct an ongoing program of outreach to potentially eligible individuals.

In addition, this legislation would make a number of other important improvements in the SSI program, including:

- — allowing individuals living in low income households to have only the actual value of in-kind assistance counted as income, instead of being subjected to any automatic one-third reduction in benefits; and
- — allowing individuals who would be eligible for SSI benefits but for the receipt of in-kind assistance to remain eligible for Medicaid benefits.

Representatives Matsui, Downey, Miller, and Roybal have also introduced the proposed "SSI Technical Amendments of 1989" (H.R. 867) and "SSI Disabled Children Act of 1989" (H.R. 868). These bills would correct numerous glitches in the operation of the current SSI program, and would also reform the definition of "disabled children" to comport with current medical practice so that certain poor children with disabilities are not excluded from eligibility for the SSI program.

Taken together, the proposals set forth in H.R. 866, H.R. 867, and H.R. 868 would represent the first major overhaul of the SSI program since its enactment in 1972. With these improvements, the SSI program would begin to fulfill the objectives it was intended to accomplish — that is, providing at least a minimally adequate guaranteed annual income to the elderly, blind, and disabled. The UAW strongly supports H.R. 866, H.R. 867, and H.R. 868 and urges the Members of these Committees and the entire Congress to give these bills their wholehearted support.

Critics of these proposals will undoubtedly complain that reforming the SSI program will cost money. The UAW flatly rejects such criticism.

The United States clearly has the financial resources to eliminate poverty among elderly, blind and disabled persons. Informed estimates say it would cost about $6 billion to accomplish this goal. The fact is that one nuclear aircraft carrier costs about $3 billion, and we are currently spending $4.1 billion on Star Wars research.[4] Thus, all that is needed is the political will to readjust our priorities so that we are spending our resources on programs and policies which promote social and economic justice.

It is important to keep in mind that, even though the various SSI reforms discussed above may cost the federal government additional funds, these expenditures will be targeted at those individuals who are most in need. Also, expansion of the SSI program to serve more poor individuals will relieve some of the pressure on state welfare programs, and thus will save the states considerable funds. Thus, reforming the SSI program is an extremely cost-effective method of addressing the problem of poverty among the elderly and other vulnerable groups.

In conclusion, the UAW believes that the SSI reforms set forth in H.R. 866, H.R. 867, and H.R. 868 should be priority items for the 101st Congress. We pledge to continue to work for their speedy enactment.

The UAW would again like to commend these Committees for their leadership in focusing public attention on the need to reform the SSI program. We appreciate the opportunity to present our views on this important subject. Thank you.

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1. U. S. House of Representatives, Committee on Ways and Means, Background Material and Data on Programs Within the Jurisdiction of the Committee on Ways and Means, 1986 edition, March 3, 1986, p 188.
2. Ibid.
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JOINT HEARING ON SSI ISSUES
MARCH 2, 1989

WRITTEN TESTIMONY OF EILEEN P. SWEENEY, STAFF ATTORNEY, NATIONAL SENIOR CITIZENS LAW CENTER

(Submitted March 17, 1989)

This testimony is being submitted at the invitation of Representative Matsui. I appreciate this opportunity to submit testimony to these two Committees on the very important issues being considered.

There are five very fine SSI bills which have been introduced, H.R. 866, 867, 868, 360 and 361. My purpose here is to discuss some of the issues which these bills address which were not the main focus of the witnesses who testified at the hearing. As a result, this statement does not address the critical need for improvements in the SSI benefit level, the assets test, or outreach.

As the witnesses at the hearing established, the need for major improvements in this program are all too apparent. While the other provisions in the three bills, H.R. 866, 867, and 868 are more modest in their scope, they essentially have the same goal: assuring that aged, blind and disabled individuals have the income and health care coverage they need. For example, if you are one of the persons to whom the $6,000/6% rule is applied, it does not matter that it is a relatively insignificant provision in the big picture, the result is as devastating to the individual as if there was no SSI program at all.

Below is a discussion of the need for the provisions included in H.R. 866, 867, and 868.

Sections 102 and 103, H.R. 866: limiting the one-third reduction and providing for Medicaid eligibility in cases where the one-third reduction applies and the result is ineligibility for SSI

In her testimony before the Select Committee on Aging in September, 1988, Peggy Smith, testifying on behalf of Carmen Lacayo, President/Executive Director of Asociacion Nacional Pro Personas Mayores, stated:

> "Other actions, too, are needed to perfect and improve S.S.I. One of the most important is to repeal the existing measure that reduces that Federal S.S.I. benefit standard by one-third when elderly recipients reside in the house of another and receive maintenance and support. That provision discourages families from helping older relatives, and it causes some aged Hispanics to be prematurely or unnecessarily institutionalized."

"The Elimination of Poverty Among the Elderly: Supplemental Security Income Reform," Hearing before the Subcommittee on Retirement Income and Employment, Select Committee on Aging, Comm. Pub. No. 100-700, page 30 (September 16, 1988).

There could not be a clearer statement of the serious problems created by the one-third reduction. Sections 102 and 103 of H.R. 868 will ameliorate some of the effects of the current rule. First, Section 102 permits a person to establish that the amount of the in-kind contribution which s/he receives is actually less in value than one-third of the benefit and that therefore SSA should reduce the benefit by a lesser amount. While this will not eliminate the one-third reduction, it will at least permit those elderly persons who reside with very low-income relatives to prove that the contributions from others in the household are less than one-third of the SSI benefit. In the very poorest households, this will result in less of the SSI benefit being withheld.

Second, there are people who do not receive SSI because of the one-third reduction. This is because they have some other source of a small income, usually Social Security or veterans' benefits. The result is that when they live in the household of another and receive support and maintenance from those in the household, this in-kind income (deemed to be equal to one-third of the benefit) when added to the other income renders the person ineligible for SSI. In many states, the result is that the person also does not receive Medicaid. Section 103 provides that even though the person will not be eligible for a cash benefit, the person will be considered to be an SSI recipient so that s/he will be eligible for Medicaid. This should help in preventing some of the problems cited by Ms. Lacayo: with Medicaid coverage in the community, it may be possible to avoid premature and/or unnecessary institutionalization for many of the nation's elderly poor.

While it would obviously be far more desirable to simply eliminate the one-third reduction entirely, these two provisions represent improvements which will dramatically limit the impact of the current provision for at least some of the elderly poor.

Section 101 of H.R. 867: Treatment of workers' compensation and unemployment compensation as earned income for SSI purposes

Currently, unemployment compensation and worker's compensation benefits which are received by an SSI recipient or the SSI recipient's spouse or, in the case of a disabled child, the SSI recipient's parent, are treated as unearned income. This means that only $20.00 of the income is disregarded. This creates very serious problems where the person, usually the spouse or parent, has been working and loses his/her job and begins to receive one of these benefits. The person's earnings were treated as earned income. This means that the person was permitted to disregard $85 plus 1/2 of the remainder from consideration for SSI purposes. As a result, when the person loses the salary but begins to receive the benefit, the purpose of which is at least partial salary replacement, the SSI recipient's eligibility is jeopardized.

Despite the fact that there is a drop in the family's income when the person loses his/her job and becomes eligible for the benefit, the difference in treatment means that the family will be treated as if they have more income for SSI purposes than when the person was working and earning far more. The provision in the bill changes this by requiring that these benefits be treated as earned income. This will assist the family in smoothing the transition from earnings to benefits and will protect the SSI recipient from loss of critically needed benefits at a time when the family is even less able to meet the person's needs than when the family member was working.

Proposed addition to the legislation: Another problem along these lines has recently been called to my attention. In cases where the parent of a disabled child is also disabled and receiving Social Security disability benefits, SSA allows the parent to keep the equivalent of the federal SSI benefit rate before deeming the rest to be available to the SSI child. SSA ignores the fact that many states also provide state supplementation. If the disabled parent had been receiving SSI instead of Social Security, SSA would not have counted either the federal SSI payment or the state supplementation. The result is that the disabled parent who receives Social Security is allocated less to live on than an SSI disabled parent. It would be very helpful if there was a provision in the statute which clarified that SSA should disregard not only the federal SSI level but also any state supplementation in determining how much of the income of the disabled parent on Social Security will be deemed to the disabled child who is applying for SSI.

Section 102 of H.R. 867: Eligibility determinations for certain months in the cases of individuals with weekly or biweekly income.

In some families where one person receives SSI, there is a worker whose income is deemed to the SSI recipient and who is paid by his or her employer on a weekly or biweekly basis. The payment formula places the SSI recipient's benefits in jeopardy every time that there is a month that has an extra pay day in it, usually when there is a fifth Friday in the month. In those months, the worker who is paid weekly receives a fifth paycheck and the person paid biweekly receives a third. To avoid the current situation where the SSI recipient loses eligibility for one month and then returns to the program the next month, this provision would require SSA to average the worker's income so that there would not be the one month in which eligibility would not be lost. This is obviously eliminates an unintended result of the placement of Fridays in the calendar and will bring some security and rationality in the SSI program to those families who have this problem.

Section 103 of H.R. 867: disregard of certain in-kind gifts

Every year when SSA is redetermining the eligibility of SSI recipients, the SSA worker asks the recipient whether they have received any income or gifts from family or friends. Invariably, some SSI recipients proudly tell of the plane, bus or train ticket which their sons, daughters, brothers or sisters sent so that the elderly or disabled SSI recipient could come to visit for the holidays. Because SSA treats this ticket as income, the SSA worker determines that, in one month, the SSI recipient was overpaid and owes SSA all or part of the SSI benefit for that month.

Apparently in an effort to mitigate some of the damage of this absurd rule, SSA has stated in one of its Social Security Rulings that it will not treat the ticket if it could not have been converted to cash by the SSI recipient. This would be the case where the recipient's relative charged the ticket to his/her credit card. If the recipient attempted to cash in the ticket, the credit would be made to the relative's account; cash would not be provided to the recipient. Under this circumstance, SSA does not count the value of the ticket as income. So, if the relative is well enough off to have a credit card, the SSI recipient is fine, but this is not so in cases where the SSI recipient's relative does not have a credit card and must pay cash.

Section 103 solves this problem in the only fair, administratively simple, fashion: these tickets would no longer be treated as income. This recognizes that the ticket was given for purposes of travel, not to subsidize food, shelter, or clothing, and that it is simply a fiction to expect that it was used any differently. This is not a costly provision. Yet, it will be very helpful in eliminating the "hassle" factor for SSI recipients and, for those who get caught in the lair of the current rule, it will mean that they will have their entire benefit when they need it.

Section 104 of H.R. 867: Reduction in time during which the income and resources of separated couples must be treated as jointly available.

As the statute is currently written, when a married couple who receive SSI separates, SSA treats them as if they are still together and sharing their income for six months after the separation. This fiction creates incredible hardship for the member of the couple, usually the wife, who has the least income. Typically, the husband will have some other source of income as well, such as a veteran's benefit. When they separate, he will get that veteran's benefit as well as 1/2 of the SSI they received (which was already reduced by his veteran's benefit) and she will have only 1/2 of the reduced SSI benefit.

> For example, Janice Sprandel resides in Maine. She is disabled and receives SSI. Her husband, Frederick, was retired and received Social Security in the amount of $366.10. While Frederick Sprandel was not eligible for SSI, he was treated as an SSI "eligible spouse" because he was over 65. The Sprandels were treated as an eligible couple. Janice Sprandel had no income of her own but her husband's benefit reduced the couple's monthly SSI benefit to $140. When the Sprandels separated, SSA paid each of them 1/2 of the $140 for six months. This meant that Janice Sprandel had $70 to live on for each of the six months while Frederick Sprandel had not only his $366 but also $70 of SSI.

This current requirement is inconsistent with the more favorable treatment which the Secretary accords to married couples who separate where only one spouse is receiving SSI and the other's income is being deemed to the SSI recipient spouse. In those cases, the individuals are treated as separated after the first month. There is no reason to do less for the couples where both are treated as receiving SSI.

Very frequently, the women who are affected by the current provision are victims of domestic violence who are trying to escape their abusive husbands. Without a full SSI benefit, they do not have any measure of economic wherewithal and are left to survive for six months on very little.

This provision in the bill addresses this problem very effectively: the couple will be treated as individuals after one month. For people like Mrs. Sprandel, that means that she will receive the full SSI benefit instead of struggling to survive on $70.00. Further, in those cases where the Secretary determines that there is a financial emergency, as one would expect with domestic violence or where the person is homeless or likely to become homeless soon, even the one month wait would be waived.

Section 106 of H.R. 867: Increase in face value of life insurance policies whose cash value is disregarded and increase in allowable burial fund.

It would be very helpful to raise the permissible levels on insurance policies and burial accounts. The provision also includes another significant improvement in the statute's burial account provision. Currently, if an SSI recipient makes a mistake and uses a portion of the burial trust for something other than burial, SSA does not apply its overpayment rules to the situation. Instead, it treats the person as being *penalized* and *cuts off the person's SSI* for as long as necessary to cover the amount that was spent. This works an incredible hardship on the unsuspecting SSI recipient.

For example, if Mrs. A's water heater explodes one cold night and she uses all or part of her burial account to meet this unexpected expense, SSA will withhold her entire SSI check until it recovers the full amount that she spent.

But, if the SSA was required to treat the situation like any other overpayment,the result for Mrs. A would be far less devastating. SSA would be required to inform Mrs. A that she had been overpaid and that she had the right to seek waiver of recovery of the overpayment if she believed that she was not at fault in creating the overpayment and if it would defeat equity and good conscience to require her to repay. If Mrs. A did not seek waiver or if her request was denied, SSA would recover the amount of the overpayment by withholding no more than 10% of her income monthly. While the 10% limit would not apply where fraud was involved, most cases would fall under the 10% rule if waiver was not granted.

This provision of the bill provides that the overpayment rules will be applied in these cases.

Section 201 of H.R. 867: Continued SSI suspension status for certain residents of public mental institutions.

In the 1984 Disability Benefits Reform Act, Congress assured that disabled beneficiaries would not lose their benefits if their conditions had not medically improved (subject to certain exceptions.) This very significant clarification in the law has brought some sense of security for many beneficiaries. There are still a few problems. One is that if a disabled SSI recipient enters a public mental institution generally his SSI benefits are suspended. The suspense status lasts for 12 months. If he leaves the institution within 12 months, benefits are reinstated. However, if he stays longer than 12 months, he must reapply for SSI. Upon reapplication, SSA does not apply the medical improvement standard. In the case of a man in Oregon, SSA denied his application despite the fact that he was just as disabled as he had been before he entered the institution. Under this provision, the suspense status would continue for the entire time that the person is in the institution. As a result, the medical improvement standard will be applied in the person's case when his case is readjudicated.

Section 301 of H.R. 867: Retention of Medicaid when SSI benefits are lost upon entitlement to Social Security spouse benefits or retired workers benefits prior to age 65.

In recent years, the Congress has taken steps to protect certain categories of people who were receiving SSI disability benefits until SSA required them to apply for a Social Security benefit when they became eligible for the benefit. As a result of receiving the Social Security benefit, the person lost SSI and Medicaid. Unfortunately, the old age benefit which the person receives does not provide for Medicare coverage until age 65. For example, in 1987, Congress provided that a disabled widow who was receiving SSI disability before she turned age 60 who was required by SSA to apply for old age spouse's benefits at age 60 would be deemed to be SSI eligible until she was 65 so that she could continue to receive Medicaid. Without this provision, she had no health care coverage from age 60 until age 65.

This bill identifies two other groups of disabled individuals who are similarly situated to these disabled widows. Mrs. B is the disabled spouse of a very low-income worker, in this case, a farmer. Because she does not have an earnings record of her own, she is not eligible for Social Security disability benefits. Instead, she receives SSI disability. When she turns age 62 and her husband is eligible for Social Security, SSA requires her to apply for spouse's retirement benefits on her husband's record. The result is that she begins receiving Social Security and if the benefit is higher than SSI, she loses her SSI and her Medicaid. However, because she is only 62 years old, she will not be entitled to receive Medicare until she is 65. This is true even though she has already been determined to be disabled by SSA and even though she needs health care coverage. Under this bill, Mrs. B will be deemed SSI eligible until she reaches age 65. This will permit her to continue to receive Medicaid until she is eligible to begin receiving Medicare.

A similar problem currently exists for workers who become disabled but who, while they will be eligible for a retirement benefit, are not able to meet the recency of work test and therefore are not eligible for a Social Security disability benefit. These individuals, if their income and resources are low enough, receive SSI disability benefits. When these individuals become 62, SSA forces them to apply for early retirement benefits. Again, they lose SSI and Medicaid, but are not entitled to receive Medicare until age 65. Under the provision of the bill, these individuals would be deemed eligible for SSI so that they could continue to receive Medicaid from ages 62 until 65.

Section 302 of H.R. 867: Retention of Medicaid for certain additional disabled adult children.

In 1986, in Public Law 99-643, Congress recognized that some young SSI disability recipients lost SSI and, thus, their connection to the Medicaid program, when their parents died, became disabled or retired and the adult "child" became entitled to Social Security dependent's benefits as the adult disabled child of the worker. The 1986 provision says that any SSI recipient who loses SSI and Medicaid as a result of becoming entitled to Social Security disabled adult child benefits on or after July 1, 1987, will be deemed eligible for SSI so that s/he can continue to receive Medicaid.

The provision in this bill recognizes that there are others who have exactly the same problem and are no longer able to receive Medicaid who first became entitled to Social Security prior to July 1, 1987. This provision would permit people in this group who first became entitled to Social Security between 1981 and July, 1987 to also be deemed SSI recipients and, as a result, to begin once again to receive Medicaid. This provision is particularly important to those individuals with disabilities who must be Medicaid eligible in order to secure placement in a community-based group home.

Section 303 of H.R. 867: Amendments affecting individuals considered to be receiving SSI for purposes of the Medicaid program.

There are now a number of categories of individuals who are permitted to retain Medicaid eligibility once their SSI cash benefits cease. Under the current procedures, when SSA notifies a person that his/her SSI benefits will be terminated, if the person falls into one of the protected categories, SSA generally states in the notice that the person may still be eligible for Medicaid and that the person should contact the state Medicaid agency. This sounds simple enough but it appears that, in fact, many of these individuals never are able to make the connection with the Medicaid program.

This provision will smooth the transition between the two programs. When the person loses SSI, if s/he is in one of the protected groups who are deemed to be receiving SSI for Medicaid purposes, SSA would simply notify the state Medicaid agency to change the person's Medicaid status and that they should readjudicate the person's eligibility. This would significantly ease the transition for a group of individuals who are all disabled and most of whom are also elderly.

Section 2 of H.R. 868: Definition of disabled children

The testimony presented at the hearing by Bill Shelton and Donna Lefebvre very clearly explain the need for drastic, immediate statutory reform of the SSI disabled children's program. Further support is provided by the case examples which were also submitted for the record. The bottom line here is that severely disabled poor children are going without the benefits which the Congress intended them to have because of rules designed by SSA to exclude many of these children. It is important not only that the statutory definition be clarified to require that SSA properly consider all of a child's impairments and limitations but also to require SSA to update the listing of impairments which it utilizes.

It is also very important that there be a mechanism which permits the youngest disabled children who are the most difficult to test to receive benefits. Then when they are old enough, their continuing eligibility can be reassessed. The current situation is ludicrous. It is common for SSA to find that a child with Down Syndrome is eligible at age 18 months, the month in which the child could be tested, but not in the preceding months even though the child's application has been pending since shortly after birth. Playing these types of bureacratic games with children who obviously have been disabled since birth is heartless and should be stopped.

Proposed addition to the legislation: In the 1984 disability amendments, Congress required the Secretary to make every reasonable effort to assure that all of the state disability determination services (DDSs) had a psychiatrist or psychologist on staff who was required to review all of the cases in which the person had a mental impairment. The Congress also instructed the Disability Advisory Committee to recommend whether there was a need for a greater roll for medical specialists in the DDSs. The Committee's recommendation was that states should use their judgment when medical specialists were needed but that they should not be mandated. This ignores the fact that there are entire categories of cases in which review by a specialist could make a significant difference in the quality and accuracy of the decision issued. One such area is pediatrics. The Congress should consider expanding the language in the 1984

Act to require that the state agencies must have disabled children's cases reviewed by a board-certified pediatrician.

Section 3 of H.R. 868: Amendments related to resources

SSA's $6,000/6% rule is a serious bar to eligibility for disabled children and some disabled spouses in families where the worker is a farmer or self-employed. Under SSA's rule, SSA will only exclude income-producing property from consideration as a resource if it is worth less than $6,000 and has at least a 6% return on investment each year. For many struggling farmers, this means that they must choose between their farms and their disabled child or spouse. For example, SSA says in the preface to its regulations that because the $6,000 rule only applies to the equity value, a farmer can simply encumber his property further in order to obtain SSI benefits for the child. However, in the spring, when the farmer goes to the bank to seek a loan for the spring planting, no bank will provide a loan where the equity is so low.

When SSA published its regulation implementing the $6,000/6% rule in 1985 (it had been using it for at least a decade before the regulation was issued), it indicated that it was relying upon a study it had done in setting the figures. In response to my Freedom of Information request for a copy of the study, SSA replied in January, 1986 that, "The survey referred to in the October 22, 1985 Federal Register no longer exists. This survey was done prior to 1974, and it is the policy of the Social Security Administration to routinely purge its records of obsolete documents."

Two courts have held that the current rule is arbitrary and capricious. See Maine Association of Interdependent Neighborhoods v. Petit, 647 F.Supp. 1312 (D. Me. 1986); Hintz v. Bowen, Civil No. A1-87-89 (D.S.D. November 30, 1987).

The simple solution to the problem is the one set forth in this bill. Instead of focusing on the value of the income-producing property, SSA should focus on the income which it generates. This is very reasonable and consistent with the treatment of income-producing property in the food stamp program. It would also make a tremendous difference to individuals with disabilities and their families. Two examples will illustrate this:

> There is a man who lives in South Dakota. He has three children, all of whom have cerebral palsy. He has a one-person beauty shop in a small town with a population of under 1,000. The shop is valued at $14,680. His income last year from the shop was $5,720. His three children have been denied SSI because, under the $6,000/6% rule, his business, which yields the family's only source of income, is worth more than $6,000. If SSA was required to focus on the income generated by the family's business, instead of the value of the business, the children would be eligible both for SSI and the Medicaid which they very much need.
>
> Brian Hintz is 17 years old and mentally retarded. He lives with his parents on their farm in North Dakota. He received SSI but his benefits were terminated because SSA found that his resources exceeded the resource level. His parents had $6,882 equity value in their livestock, machinery and vehicles. On appeal, the administrative law judge found that the family's farming operation was "barely marginal. They have an inadequate acreage basis and their machinery is

> old and of little use or value. It is apparent they are in need of the supplemental security income payments made to their son, Brian." However, because of the $6,000/6% rule, the ALJ found that Brian was not eligible. This decision stood until a federal district court held that the rule was arbitrary and capricious.

Section 4 of H.R. 868: SSI disabled and blind children eligible for Medicaid in all states

It surprises many people to learn that even if a disabled child is somehow able to establish eligibility for SSI, they may still not be eligible for Medicaid in some states. This is because of the §209(b) Medicaid option which fourteen states have exercised. Section 4 recognizes the critical importance which not only SSI but also Medicaid serve in addressing both the immediate and long-term health needs of the child with disabilities. Under this provision, any child who establishes eligibility for SSI would also be eligible for Medicaid, without regard to where his or her family happens to reside.

Conclusion

Thank you for considering this statement. These bills will make significant improvements in the lives of both SSI recipients and those who should be SSI recipients but currently are not.

STATEMENT OF DIXIE HENRY, ESQ., VERMONT DEVELOPMENTAL DISABILITIES LAW PROJECT, BURLINGTON, VERMONT

My name is Dixie Henry and I am a staff attorney at the Vermont Developmental Disabilities Law Project. I submit these comments on behalf of Linda Sherwood, Donna Hartwell, Margaret Prim, Beulah Berard and Catherine Potter.

Linda Sherwood is the mother of Rebecca and Nicholas Spaziani. Rebecca is seven years of age and Nicholas is five. Both children have Hirschprung's Disease which is a congenital disease involving the failure of ganglion cells to develop in portions of the large intestine (colon). Ganglion cells are necessary for peristalsis or the squeezing action that moves waste material through the intestine. Without ganglion cells, this cannot be done. Symptoms include intestinal obstructions, inflammation of the colon and/or bacterial overgrowth. A child with Hirschsprung's Disease often has abdominal distention, dehydration, diarreah, and vomiting.

Rebecca and Nicholas require constant care to remove the waste material their young bodies cannot expel normally. They are frequently hospitalized. They must take medication daily.

Medicaid currently pays for their medical care. They receive Medicaid because they receive ANFC. Their mother, Linda Sherwood, applied for Supplemental Security Income (SSI) for the children in an effort to receive SSI linked Medicaid so she could go to work and not be dependent on ANFC. Linda Sherwood is a single parent. She participates in Vermont's Reach-Up Program and has been working and volunteering full-time for the past two years.

Rebecca and Nicholas Spaziani were both denied SSI benefits due to a finding that their impairments do not meet or equal a listed impairment. There is no listed impairment for Hirschsprung's Disease. The denials have been appealed. At the hearing before a Social Security Administration Administrative Law Judge (ALJ), the ALJ informed Ms. Sherwood that the only relevant information was medical and he would determine their claims based on the listed impairments. No description of the extensive daily care the children receive, frequent illnesses, or hospitalizations, pain or function limitations imposed by this disease is contained in a listed impairment.

While Ms. Sherwood waits for a determination on her children's SSI claims she must remain on ANFC to receive Medicaid. This is the only way she can ensure the children will receive the medical care they require.

Donna Hartwell is the mother of Valerie Hartwell. Valerie is seventeen years of age and has cystic fibrosis, diabetes, bronchial asthma, allergies and scoliosis. She has been denied SSI because her impairments were compared individually to each relevant listed impairment. Valerie Hartwell is frequently hospitalized; she requires daily physical chest therapy, is seen at the cystic fibrosis clinic every two to three months and a by local doctor in between visits. Valerie Hartwell must check her blood sugar two times daily with a stick test, pricking her finger to draw blood. She takes over forty (40) prescribed medications daily. Her claim for SSI was denied at each level of the Social Security administrative review process. She has filed an action in United States District Court for review of the denial of her claim. Ms. Hartwell filed the SSI claim appealed from on September 3, 1985. Valerie Hartwell will be eighteen in June 1989. Significantly, the listing of impairments does not contain an adult listing for cystic fibrosis. Presumably, this is because few children with this disease survive to adulthood.

Margaret Prim is the mother of a five year old autistic son who receives SSI. However, when her husband was seriously injured at work and he received Worker's Compensation, her son's SSI check was reduced. A reduction in the family income caused the SSI check to be reduced because Social Security treats Worker's Compensation as unearned income. A letter from Ms. Prim is attached. The hardship is obvious. This child received SSI when his father was working. When his father was injured and unable to work, the child received less in SSI, although his needs remained constant and the available family income was reduced.

Beulah Berard and Catherine Potter have both suffered significant financial hardship as a result of the six-month separation rule for SSI eligible couples. That rule requires the couple to be separated for six months before the members of the couple are eligible for the SSI individual rate. In Beulah Berard's case, the separation occurred because her husband was forced to enter a residential care home for medical reasons. In Catherine Potter's situation, she was forced to leave the home to escape her abusive husband. She was left with only $59 per month in SSI benefits for the six month period. When she took shelter in her daughter's home, Social Security determined that she was not paying her fair share in the household of another and took away the $59 as well. When an SSI eligible couple separates, the members have an immediate need for income to meet their basic needs individually.

These individual circumstances demonstrate the critical need for the proposed amendments to the SSI Program. Thank you for the opportunity to comment.

James and Margaret Prim
45 Red Clover Way
Milton, Vermont 05468

March 1, 1989

To Whom It May Concern:

In October of 1987, my husband was in an accident while on his job. He suffered from severe cervical whiplash. He had to wear a collar and took medication for the pain. He no longer could drive himself anywhere and could not work. Doctors and therapy took up most of the available time in a day for months. Workman's Comp. began approximately one week after the accident with the persistence of legal counsel but was very erratic. It came, but sometimes it would be 1 1/2 to 2 weeks between checks. My son's SSI check was the only thing that I could count on being the same. I never dreamed that my son's SSI benefit would go down when my husband got hurt and our income decreased.

Since my husband was bringing in less money now and we were spending more (gas and car upkeep) the SSI was a blessing. Our debts didn't go away just because he wasn't able to work. Many weeks the Food Shelf was our only source of food.

Our family was falling apart. My then 11 year old had just started counseling, trying to adjust to the death of her oldest sister, two months before the accident. My 16 year old left home to live with her natural father and my five year old autistic son screamed constantly because he didn't understand what was going on around him.

I knew that income changes are generally supposed to be reported but I never dreamed that we would have to live below poverty level because of something we had no control over. My son was already getting the maximum SSI benefit, so I did not realize that my husband's loss of income would affect the SSI. In fact, as my Legal Aid lawyer has explained to me, Workers Compensation is treated as unearned income, so the switch from a paycheck to a (smaller) Workers Comp check meant less SSI for my son. Now we have been assessed a $434 overpayment, which is reducing my son's SSI still further, and an Administrative Law Judge has refused to waive it. We are still appealing this decision.

I wouldn't have guessed that my son would be made to live like this by the very people who are supposed to be there to help. I still find it hard to believe.

Margaret Prim

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